

PROLONGED GRIEF IN LIMB LOSS: A MIXED DESIGN STUDY

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ABSTRACT

PROLONGED GRIEF IN LIMB LOSS: A MIXED DESIGN STUDY

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Human beings are prone to loss or threat to lose in each stage of life, and the grief is inevitable. However, if the grief process becomes incomplete and lasts more than expected, mourners suffer from Prolonged Grief Disorder (PGD). This study aimed to examine the role of the PGD in an amputee sample and was planned to be two-folded using both quantitative and qualitative methods. In the first study, it was aimed to examine the relationship among prolonged grief, psychological symptoms, the association of frequency and intensity of perceived residual and phantom pain and residual pain to prolonged grief of amputees on individuals losing limb. In the second study, how prolonged grief was experienced by individuals losing body part(s) was examined by the aid of Interpretative Phenomenological Analysis (IPA). In study 1, it was revealed that 25.2% of participants in Study 1 fit the criteria of PG-13. Perceived residual and phantom limb pain in terms of frequency and severity was found significantly associated with PGD. Moreover, perceived existence of residual and phantom limb sensation, time pass post amputation, perceived nature of loss, giving

the decision of being amputated might be the determinants or factors affecting the possibility of PGD. In Study 2, four superordinate themes were emerged which are: 1) life & death or amputation has two subordinate themes which are *surviving with the cost of limb loss, and the test in life*, 2) absence of limb, 3) holding on life and 4) still there according to IPA. The results of two studies were congruent that amputees might suffer from PGD and grief therapy might be useful for those having adjustment problems following an amputation.

Keywords: Prolonged Grief, Amputation, Losing Limb, Interpretative Phenomenological Analysis.

ÖZ

UZUV KAYBINDA UZAMIŞ YAS: MİKST DESENİLİ BİR ARAŞTIRMA

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İnsan hayatının her aşamasında kaybetmeye veya kaybetme tehdidine yatkındır ve yas kaçınılmazdır. Yas süreci tamamlanmadığında ya da beklenenden uzun sürdüğünde, yas tutanlar Uzamış Yas Bozukluğu (UYB) ndan muzdarip olabilirler. Bu çalışma, amputelerde UYB'nin rolünü araştırmayı amaçlamıştır ve nitel ve nicel yöntemlerin kullanılması planlanmasıyla iki yönlüdür. İlk çalışmada, uzamış yaş, psikolojik belirtiler ve algılanan güdük ve fantom ağrıların sıklık ve şiddeti arasındaki ilişkinin incelenmesi amaçlanmıştır. İkinci çalışmada, uzuv kaybı olan bireylerin uzamış yası nasıl deneyimlediği Yorumlayıcı Fenomenolojik Analiz (YFA) yardımıyla incelenmiştir. Çalışma 1'de katılımcıların %25.2'sinin UYB kriterlerini sağladığı görülmüştür. Algılanan güdük ve fantom ağrıları hem sıklık hem şiddetleri açısından UYB ile ilişkili çıkmıştır. Ayrıca, algılanan güdük ve fantom ağrı ve duyularının, amputasyon sonrası geçen sürenin, gerçek kayıp sebebinden ziyade kaybın algılanan beklenmedik doğasının, amputasyon kararını vermenin UYB olasılığına etki eden faktörler olabileceği düşünülmüştür. Çalışma 2'de, YFA bulgularına göre 1) yaşam &

ölüm ya da ampütasyon, *uzuv kaybı bedeliyle hayatta kalma ve yaşam sınavı*, 2) uzvun yokluğu, 3) hayata tutunmak, ve 4) halen orda olmak üzere dört üst tema bulunmuştur. İki çalışmanın sonuçlarının birbiriyle uyumlu olduğu göz önünde bulundurularak ampüterlerin UYB'den muzdarip olabileceği ve yas terapisinin ampütasyonu tabiben uyum problemi yaşayan ampüteler için faydalı olabileceği tartışılmıştır.

Keywords: Uzamış Yas, Ampütasyon, Uzuv Kaybı Yorumlayıcı Fenomenolojik Analiz.

To the ones unheard...
For the sake of recognition...

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CHAPTER 1

INTRODUCTION

Grief is inevitable in each stage of life due to inevitability of the loss. Even though grief literature mostly focuses on the death of loved ones, losing ideals, a divorce, or a friend moving to another city might be experienced as a loss (Bildik, 2013; Jeffreys, 2011, Volkan, & Zintl, 2010). Therefore, grief reactions can be observed. There are variable terms interchangeably used to describe the process after loss which are mourning, bereavement and grief (Jeffreys, 2011). Mourning is defined as the process of one's experiences after loss including the adaptation to the loss (Worden, 2018). On the other hand, Shear (2017) declared that "grief cannot be simplified to one definition but rather a shorthand term for a complex multicomponent experience that varies and evolves over time whose specific features are unique to each individual and each loss". Grief is a complex and dynamic process varying among cultures (Jeffreys, 2011). Additionally, bereavement is a more specific experience of grief and involves trying to adapt after losing someone close (Worden, 2018).

Grief reactions grasps a broad range of feelings, cognitions, physical sensations, and behavioral reactions after a loss (Worden, 2018). Sadness, anger, blaming both the self and the deceased one, guilt and self-reproach, anxiety, loneliness, fatigue, helplessness, shock, numb, yearning, emancipation, relief, numbness, hollowness in the stomach, tightness in the chest, tightness in the throat, oversensitivity to noise, a sense of depersonalization, breathlessness, feeling short of breath, weakness in the muscle, lack of energy, dry, disbelief, denial, confusion, preoccupation, sense of presence, hallucinations can be the experiences of mourners (Jeffreys, 2011; Worden, 2018). However, mourning might be longer than expected or somehow disrupted resulted in incompleteness of grieving that mourner's occupation with the loss decrease their functionality socially and vocationally. Perceived closeness with the deceased

and perceived relationship quality, nature of the loss, history of prolonged grief, and consequently personal capacity of grief, unexpected personality characters, social factors, multiple and/or sequential losses, and the unfulfilled childhood needs, cultural values inhibiting mourning might be risk factors for prolonged grief. Additionally, grief as a disorder gains importance and becoming focus of attention among mainstream mental health area in the name of “Persistent Complex Bereavement Disorder” (PCBD) (DSM-5, 2013), “Prolonged Grief Disorder” (PGD) (ICD-11, 2018).

To conclude, while losing a close one is described as losing a body part for mourner in the literature, it is surprising that losing body part(s) physically is not well-documented. What about the grief processes of amputees? Do amputees suffer from prolonged grief like the ones losing their loved ones?

Limb loss is a life-changing circumstance bringing physical, psychological, social and environmental change at a time (Peirano, & Franz, 2012). Individuals losing limb might experience grief reactions and suffer from prolonged grief which might result in challenges in the adaptation to this novel condition. Actually, amputees do not only lose their limb(s), but also lose their “normal” identity and gain an identity with disability, loses body integrity which results in hopelessness, decrease in locus of control, self-esteem, belief systems, social isolation (Oğul, & Erden, 2005; Öznur, 2013). Amputees suffer from elevated depression and anxiety levels (McKechnie, and John, 2014; Uzun, et al., 2003) additionally from residual and phantom limb pain (Crawford, 2014; Hogan, et al., 2022) even after long years from amputation. Therefore, the question arises whether prolonged grief has a role in these long years of suffering of amputees.

All in all, when the literature was taken into consideration, this distertation was designed as two-folded using both quantitative and qualitative methods. In the first study, it was aimed to examine the relationship among prolonged grief, psychological symptoms, the association of frequency and intensity of perceived residual and phantom pain and residual pain to prolonged grief of amputees on individuals losing limb. In the second study, how prolonged grief was experienced by individuals losing body part(s) was examined by the aid of Interpretative Phenomenological Analysis.

1.1 Loss and Grief

Human beings are prone to loss or threat to lose in each stage of life. When the loss and grief literature is examined, it mostly focuses on the death and dying concepts (Jeffreys, 2011; Worden, 2018). However, “faces of loss” vary in a broad range, such as end of a relationship; loss of a loved one or a lover, a job or an earring; losing organs, ideals, freedom, hope and even identity; a friend moving to another city, and a stolen wallet. Moreover, changes also might bring grief; for example, a promotion, marriage, and a newborn baby. Loss can also be felt after winning the lottery as loss of previous life, surprisingly resulting in depression (Bildik, 2013; Jeffreys, 2011, Volkan, & Zintl, 2010) However, there are several terms interchangeably used to describe the process after loss which are mourning, bereavement and grief (Jeffreys, 2011).

Mourning or feelings after any kind of loss are actually psychological reactions and negotiations to be able to adapt between internal world and outside reality (Freud, 1917; Lindemann, 1944; Volkan, & Zintl, 2010). Even if it is hard to call some feelings after experiencing desired events as mourning, unexpected tears of graduation, marriage, and moving to a new house might be indicators of mourning (Volkan, 2017). Mourning is defined as the process of one’s experiences after loss including the adaptation to the loss (Worden, 2018). In addition to these definitions, Engel (1961) describes mourning as the process of re-gaining functionality after loss. To conclude, mourning is an internal job where mourners are recruited following a loss for a specific amount of time.

On the other hand, grief can be explained as a universal and natural response to bereavement after losing a loved one (Shear, 2017). Grief accompanies mourning. (Freud, 1917; Lindemann, 1944; Volkan, & Zintl, 2010). According to Shear (2017, p17) “grief cannot be simplified to one definition but rather a shorthand term for a complex multicomponent experience that varies and evolves over time whose specific features are unique to each individual and each loss”. Grief is a complex and dynamic process varying among cultures (Jeffreys, 2011).

Additionally, bereavement is a more specific experience of grief and involves trying to adopt after losing someone close (Worden, 2018). Bereavement can also be explained from attachment perspective as “acute attachment security”. Loss of someone loved is experienced as painful because when the person has gone, mourner might be no longer safe (Shear, 2017). After a loss, finding “a new normal” can simply be defined as the adaptation process (Worden, 2018). Another discrimination of these terms is that grief is regarded as internal reactions, mourning as observable behaviors to loss and bereavement as cultural and societal roles after loss (Jeffreys, 2011).

According to the developmental model of grief, there are three stages; early grief: reacting, middle grief: reconstructing, and later grief: reorienting. In the early stage of grief, weeks after loss, mourner reacts to the loss and questions how and why this happened. In this stage, self-acceptance can be reached. In the middle grief stage, mourner reconstructs the loss and looks for a novel location for the loved one. At the end of the stage, continuing bond can be discovered. Consequently, in the later grief stage, mourner reorients the self and defines who they are now. Therefore, posttraumatic grief can be gained (Neimeyer, & Cacciatore, 2016).

1.1.1 Grief Reactions

Normal grief is also called as uncomplicated grief (Worden, 2018; Volkan, & Zintl, 2010) grasps a broad range of feelings, cognitions, physical sensations, and behavioral reactions after a loss (Worden, 2018). Grief reactions vary from adjustment to the serious crisis (Bildik, 2013). Many factors affect the nature of each individual’s grief reaction. A traumatic loss might trigger to recall a memory and its associated feelings, sights, sounds, smells and bodily sensations resulting in merging of an older grief feeling with the current one (Jeffreys, 2011).

Lindeman (1944) describes five characteristics of grief which are 1) somatic or bodily distress of some type, 2) preoccupation with the image of the deceased, 3) guilt relating to the deceased or circumstances of the death, 4) hostile reactions, 5) the inability to function as one had before the loss. Additionally, he contributed to these five reactions that mourners may develop on their own behavior resembling to the deceased one (as cited in Worden, 2018).

Several feelings might emerge simultaneously at the same time or in different time episodes after a loss which are sadness, anger, blaming both the self and the deceased one, guilt and self-reproach, anxiety, loneliness, fatigue, helplessness, shock, numb, yearning, emancipation, relief, numbness (Worden, 2018).

On the other hand, varied physical sensations might be experienced by mourners which are; hollowness in the stomach, tightness in the chest, tightness in the throat, oversensitivity to noise, a sense of depersonalization, breathlessness, feeling short of breath, weakness in the muscle, lack of energy, dry mouth (Worden, 2018).

Additionally, disbelief, denial, confusion, preoccupation, sense of presence, hallucinations can be the cognitive side of grieving (Jeffreys, 2011; Worden, 2018). According Boelen (2008), mourning is a process that the idea of loss was getting integrated to the autobiographical memory which can be hindered by negative beliefs and catastrophic misinterpretations of grief reactions, and anxious and depressive avoidance strategies. Furthermore, grief reactions might be observed as sleeping and eating disturbances, distracted and absentminded behavior, social withdrawal, dreaming of the deceased, avoiding the reminders of the deceased, searching and calling out, sighing, restless hyperactivity, crying, visiting places or carrying objects reminding the deceased, giving overimportance to the objects belong the deceased from a behavioral perspective (Jeffreys, 2011; Worden, 2018).

To conclude, all these grief reactions might be experienced in different phases of mourning process. However, bereavement includes cultural values how to mourn.

1.1.2 Grief as an Abnormality

Even though grief is an expected “normal” reaction to the loss, mourning sometimes becomes incomplete and persistent endangering distress to the mourner’s life and functionality after the loss attracting attention of mental health workers. The phenomenon was called with plenty of terms such as chronic grief, delayed grief, absent grief, and complicated bereavement (Worden, 2018). Grief literature has a tremendous amount of study focused on unresolved grief which is also called as pathological, complicated or prolonged grief. These terms used mostly interchangeably. However, it is called as “prolonged grief” (PG) in the current paper

as an umbrella term which both includes the meaning as the grief is still in getting processed but it lasts more than it is expected.

Uncompleted grief of losses and maladaptating to the changes consume the life energy and ruptures the natural ability to connect (Volkan, & Zintl, 2010). Worden (2018) claims that relational factors, circumstantial factors, personal history of complicated grief, personality, social factors affect the type, intensity and duration of grief. Similarly, Volkan and Zynl (2010) indicates three important factors to be able to understand grief better. Firstly, each loss drags the individual to an inevitable grief. Second one is that each loss reanimates the past losses. Third one is that each loss can be a tool to growth and renovation if the grief can be completed. According to Worden (2018), especially multi-losses is a risk factor for prolonged grief in addition to those. Furthermore, four elements might deteriorate the mourning process. First one is the unfulfilled childhood needs and individuals having sequential losses resulting in being unable to grieve. Second one, the unique nature of the relationship which can be dependent or loss of unfinished business making the process harder. Thirdly, conditions of the loss such as unexpected or sudden losses makes the acceptance of loss harder. Fourth factor is that societal limitations of the expression of grief in modern life. (Volkan, & Zintl, 2010).

Complicated grief emerges when adaptation process fails somehow or does not occur while acute/normal grief reactions still lasting by complicating the processes (Shear, Boelen, & Neimeyer, 2011). Similarly, prolonged grief can be described as intense longing and yearning, avoidance of reminders, difficulty accepting the death, bitterness, numbness, and social/identity disruption after a loss (Prigerson et al., 2009).

To sum up, perceived closeness with the deceased and perceived relationship quality, nature of the loss, history of prolonged grief, and consequently personal capacity of grief, unexpected personality characters, social factors, multiple and/or sequential losses, and the unfulfilled childhood needs, cultural values inhibiting mourning might be risk factors for prolonged grief. Moreover, all these factors might result in serious ruptures in mourner's functionality in their vocational and social life, and the sense of identity.

1.1.3. Grief as a Diagnose

As it was in the conceptualization and naming the prolonged grief, PG as a diagnosis has several names such as “Persistent Complex Bereavement Disorder” (PCBD), “Prolonged Grief Disorder” (PGD).

The most recent proposed criteria for PGD hold that one must experience severe yearning for the deceased and/or cognitive preoccupation with the deceased and three of five additional symptoms (i.e., difficulty accepting the loss, feelings of guilt, feelings of anger, feeling a part of oneself died, difficulty engaging in new activities), impairment in functionality socially, vocationally until at least six months after bereavement (Maercker et al., 2013; Prigerson et al., 2009). The identification of PGD fostered the issue of whether to include the condition as an official mental disorder in the diagnostic manuals (Lundoff, et al., 2017). PGD was included to International Classification of Diseases’ last version (ICD-11) in 2018 as PGD. While there are seven diagnostic criteria in the first version, there were twelve diagnostic features regarding no specification of the accessory symptom’s threshold (Killikelly, & Maercker, 2018; WHO, 2018). The first criteria include death of someone with whom he or she had a close relationship, and time and impairment criteria and the symptoms expected was congruent with the previous researchers and with their work.

On the other hand, American Psychiatric Association (2013) proposed “Persistent Complex Bereavement Disorder” (PCBD) under the title of “Conditions for Further Study”. DSM-5 determined the persistency of the symptoms at least 12 months for bereaved adults to be able to be diagnosed after a loss of loved one, at least one of four separation distress symptoms (persistent yearning, intense sorrow and emotional pain to death, preoccupation with deceased and with circumstances of the death), at least one of six reaction to death (difficulty in accepting the death, experiencing disbelief or emotional numbness over loss, difficulty with positive reminiscing about the deceased, bitterness or anger to the loss, maladaptive appraisals about oneself in relation to the deceased or the death, excessive avoidance of reminders of the loss), six additional symptoms for social and identity disruption (a desire to die to be with deceased, difficulty in trusting others, feeling alone and detached, feeling that life is meaningless or empty, difficulty or reluctance to pursue interests) and the functional impairment

socially and occupationally with the final condition of culturally, religiously and age-related inappropriate proportion (DSM-5, 2013). Time criteria is different in DSM-5 from other researchers' and ICD-11's criteria as 12 months for adults.

In Psychodynamic Diagnostic Manual-2 (PDM-2) Persistent Complex Bereavement Disorder (Complex Grief) was categorized under the Subjective Experience Axis of Event-and Stressor Related Disorders (Lingiardi, & McWilliams, 2017). Even though affective states such as intense yearning, longing, sadness, etc. and cognitive patterns such as preoccupation with recurring thoughts, images and memories of deceased and avoidance of reminders was quite congruent with the research; somatic states such as disturbed sleep without nightmares, eating disruptions due to association with the deceased can be regarded as a discriminant contribution in order to diagnose PBCD for elderly population (Lingiardi, & McWilliams, 2017).

Despite the fact that there is no consensus about naming PG, there is a necessity for one single measurement instrument, grasping each corner of prolonged grief containing varied criteria sets to be made it possible to compare diagnostic features (Lenferik, et al., 2022) and also reach more concrete prevalence rates of the PG.

1.1.4. The relationship between Prolonged Grief and Psychological Variables

When the diagnosis criteria of PCBD and PGD are taken into consideration, it is noticeable to be comorbid with several disorders and coexist with varied symptoms which is already described and diagnosed for years. According to literature, prolonged grief is positively associated with PTSD (post-traumatic stress disorder) in terms of intrusions of deceased (Simon et al., 2007). Moreover, PG coexists with depression and anxiety symptoms, but also has a unique effect on the life quality of mourners (Boelen and Prigerson, 2007; Boelen & van den Bout, 2005; Dillen, Fontaine, & Verhofstadt-Denève, 2009). After a loss, depression and PG might be comorbid, only PG might emerge or not at all according to 3-class model in both western and non-western cultures (Boelen, et al., 2016; Kokou-Kpolou, et al., 2021). Despite the fact that PG might be comorbid with varied psychological outcomes, preoccupation with the loss rather than the self in depression or the incident in PTSD primarily underlines the unique contribution of PG in the literature.

In conclusion, when grief literature was investigated, it mostly based on the grief experience of loss of loved ones; spouses, parents, siblings. However, there is a gap investigating the prolonged grief experience of individuals losing body parts. Even though “losing a loved one is alike losing a body part” is used commonly in the literature, it brings the question “what does losing limb mean to a person?” and “in which way it is similar to and different than the losing loved ones?”

1.2. Losing Body Parts: Amputation

Losing body parts might cause not only changes in body but also in the way how individuals perceive themselves, the others and the world post amputation. In addition, losing body part is not only just alterations in function but also in the activities and roles can be accomplished (Maguire, & Parkes, 1998). People lose their body integrity due to expected and unexpected causes. An arm, a nose, a testicle, and breasts can be the ones given up after a medical diagnosis or a leg after an explosion requiring changes to be adapted and to be able to re-gain the healthy status. Amputation can be defined as cutting the protrusion of a body part or a particular organ in whole or in part by the aid of surgical methods (Öznur, 2013). On the other hand, losing internal organs cause a perception of loss in functionality and decrease in health quality and social roles at the same time. Mastectomy also included as a limb loss however it does not a functional loss but the loss of perception in the body image and wholeness (Maguire, & Parkes, 1998). Therefore, each amputation type has its own specific challenging qualities peculiar to them depending on its function, visibility and representations.

Almost 185.000 amputations occur in the USA each year (National Limb Loss Center, 1998). There are 2.1 million people experiencing limb loss just in America and it is expected to be doubled by 2050 (Ziegler-Graham, et al., 2008). However, statistics for Turkey is still lack of accurate information in terms of prevalence rates. The reason of amputations can vary in medical reasons like vascular diseases, diabetes, infection or tumors and also birth defects restraining use of prosthesis, and traumatic incidents like traffic accidents, explosions, work related accidents (Belon and Vigoda, 2014; Sümer, et al., 2008; Öznur, 2013; Özsoy, & Okyayuz, 2016). The reason of amputations, mainly caused by vascular diseases (54%) following trauma (45%) and cancer (2%) (Ziegler-Graham, et al., 2008). Amputations can be regarded as a psychological trauma

which brings the danger of losing the body integrity, hopelessness, decrease in locus of control, self-esteem, belief systems, social isolation (Oğul, & Erden, 2005; Öznur, 2013). Therefore, professionals are required to recognize those aspects for the sake of amputee's rehabilitation process (Belon and Vigoda, 2014).

1.2.1 Psychological Outcome of Amputation

Amputation of a limb results in multiple alterations in one's life which is not only in physically but also psychologically, emotionally, socially and financially (Belon, and Vigoda, 2014). Amputation, independent from its cause catastrophic or secondary to chronic source disease process, results in a personal loss, both real and symbolic (Forducey, Ruwe, & Kaur, 2006). Fifty percent of amputees need psychological interventions (Frierson, & Lippmann, 1987). Initially, amputees have to adjust their current body physically as they already have lost their one or more than one body parts which are very novel situation for them on their own (Rybarczyk, Szymanski, & Nicholas, 2000). They may also need to use prosthesis in order to increase their functionality and mobility after the recovery of amputation surgery (Belon and Vigoda, 2014). Even while some feel incomplete or whole (Belon and Vigoda, 2014), this may also bring another adjustment process for the artificial organ. As physical and psychological factors are co-dependent in the rehabilitation of amputations, most of amputees report residual pain and phantom limb pain which may cause interference of daily activities including recreational and social activities, communication, self-care and learning new skills (Randolph, Nelson, & Highsmith, 2016).

Disability after amputation is not just producing consequences in one's physical health but also affects the psychological health of the individuals (Forducey, Ruwe, & Kaur, 2006). Because of their physical disfigurement, amputees may feel less attractive than before amputation even if it is hardly noticeable by other (Belon and Vigoda, 2014, Ward-Khan, et al. 2019). The psychological effects of amputation vary in a broad range based on many factors, such as person's age, personality traits, coping skills, flexibility, presence of social support, coexisting medical conditions, and whether the amputation is planned or sudden (Forducey, Ruwe, & Kaur, 2006). This is why they are required to attend to the rehabilitation in the long run for their psychosocial adjustment of post amputation (Oğul, & Erden, 2005). Individuals do not have

adequate time to being prepared mentally to the amputation due to the sudden loss of body parts react to the amputation with denial (Forducey, Ruwe, & Kaur, 2006). Sometimes they are needed to be confronted that they will never be like the same as before they are (Belon and Vigoda, 2014). Longitudinal studies reveal that individuals losing body parts still have many psychological symptoms and phantom limb pain even after 2 years (Horgan, & MacLachlan, 2009; Hunter, et al., 2008; Pedras et al., 2018). Likewise, the grief reactions, adaptation to losing body parts also varies person to person when individual cases are taken into consideration (Rybarczyk, Edwards, & Behel, 2004; Spiess, et al., 2014).

Studies reveal that individuals losing body parts are facing with depression, anxiety, body image, feelings of vulnerability, social support changes, grief, pre-amputation psychological issues and phantom limb pain and sensations (Rybarczyk, Edwards, & Behel, 2004). However, studies do not focus on especially grief processes of amputees (Rybarczyk, Edwards, & Behel, 2004).

Rybarczyk, Edwards, and Behel (2004) demonstrated that each individual has their own unique reaction and adjustment process with their acquired disability in the reported cases from an inpatient rehabilitation service. Psychological aspects of rehabilitation are affected by the meaning of amputation and the way it is perceived for this person (Özsoy, & Okyayuz, 2016). During this process, grieving is a natural and normal emotional response that all amputees experience for their loss of organ and body integrity after the amputation like grieving for death of someone loved (Belon and Vigoda, 2014). Loss a limb is mostly regarded as equal to the death of a loved one and also frequently followed by a period of grieving (Forducey, Ruwe, & Kaur, 2006). Grief stages of Kubler-Ross which are denial, anger, bargaining, depression, and acceptance can be experienced in a varied order (Forducey, Ruwe, & Kaur, 2006). Furthermore, somatic symptoms are common in the early stages of loss (Forducey, Ruwe, & Kaur, 2006).

Findings revealed that adjustment to the amputation depends on the psychological, developmental and also social resources of the individuals rather than the physical qualities of the amputation (Asano, et al.,2008). In the effective rehabilitation of individuals with amputation, it is imperative to assess the emotional adjustments of

individuals to change. This is why health workers should also work on the psychological aspects of this specific group (Forducey, Ruwe, & Kaur, 2006). Moreover, the development of effective coping strategies is required for the sake of the physical and emotional functional well-being of the amputees. However, most of amputees report psychological disturbances and symptoms (McKechnie, & John, 2014) even after long years of post-amputation (almost after 10 years) (Hill, Niven, & Knussen, 1995; Öznur, 2013) and also ongoing problems residual limb, phantom pain, wounds and sores (Pezzin, Dillingham, and MacKenzie, 2000). It is regarded that one psychosocial factor might precipitate the other ones such as unemployment, relationship problems, substance dependency (McKechnie, & John, 2014). In the systematic review of McKechnie, and John (2014), post-amputees showed 20.6-63% depression and 25.45-57% anxiety even after 2 years after being amputated. On the other hand, prevalence of developing a psychological disturbance might also be related to the reason of amputation. Uzun, Yıldız, Ateş, Cansever and Ateşalp (2003) demonstrated that prevalence of depression was higher (51.4%) in surgical amputee group than traumatic amputee group (34.7%). Depression of traumatic amputee group was found to be associated with time since loss; however, depression scores of surgical amputees was associated with age, educational level, marital status, socio-economic status and time since amputation.

Although there are a tremendous amount of study revealing the positive effect of social support with the adjustment of losing body parts (Oaksford, Cuddihy, & Frude, 2005), some studies demonstrates that some individuals still stand in a pessimistic point of view with difficult adjustment to amputation and high level of emotional distress in spite of high level of social support (Liu, Williams, Liu, & Chien, 2010).

Psychotherapy and grief work can be effective method to decrease psychological distress, depression, anxiety, and also chronic phantom limb pain (Schneider, Hofmann, Rost, & Shapiro, 2008; Srivastava, & Chaudhury, 2014). Health professionals are required to understand better the needs of amputees and also expand their scope in terms of rehabilitation and adjustment from physical and prosthetic focus to psychologically supportive and treating (Liu, Williams, Liu, & Chien, 2010).

In short, adjustment to the amputation is a complex process that both physical and psychosocial factors interplay (Rybarczyk, Szymanski, & Nicholas, 2000). This makes essential the screening of the amputees' emotional responses after surgery and throughout the rehabilitation process whether it is physical or psychological in order to determine the type of intervention.

1.2.2 Phantom Limb Pain

According to National Survey of America, %95 of amputees declared that they at least 1 amputation-related pain in duration of 4 weeks which almost %80 of amputees had phantom pain, 67.7% of them reporting residual limb pain and 62.3% back pain (Hogan, et al., 2022). Phantom limbs are phenomena affected by multiple dimensions regarded as neurophysiological as well as psychological and social which means it is related for personal, interpersonal (especially familial), and social value of physical body parts changes (Crawford, 2014). Researchers discriminates phantom limb pain and sensations from residual pain. While residual pain is described as pain in the scar area and outside of the extremity, phantom pain limb is perceived and disturbing pain in the absent limb and phantom sensations are the senses in the absent limb except the pain (Ribbers, Mulder, & Rijken, 1989; Culp, & Abdi, 2022). According to nerve irritation theory, damaged nerves alone is responsible of phantom pain and sensations. (Crawford, 2014). Phantom limbs hold a place in amputees' mental capacity and causes them to feel more uncertain about their own self and others as the phenomena keeps its secret (Crawford, 2014). On the other hand, body scheme theory claims that birthed physical body also represents the way the individuals stating in the world that phantom limb and pain can be refusal of mutilation and lost integrity (Crawford, 2014). There is an assumption that phantom limb pain might be regarded as unresolved grief or psychosomatic reaction to the loss of their organ (Belon, and Vigoda, 2014).

1.2.3. Qualitative Studies about Amputation

As the experience of post amputation has a multifaced dimensions in both physiological and psychological ways, number of qualitative researches are increasing.

The research of Liu, Williams, Liu, and Chien (2010) can be regarded as the pioneer study focusing on the experience of being lower extremity amputation. According to

Colaizzi's phenomenological analysis findings, four themes emerged which are 'lost in the dark woods', 'emotional collapse', 'difficulty in passing through the shadow' and 'igniting a gleam of hope'. Findings especially points out that endless subjective suffering of losing limb stems from "they would never again be treated as a 'normal' person" even if there is no physical pain (Liu, Williams, Liu, & Chien, 2010). It can be inferred that amputees lose their 'normal' identity which they had when they were born and can be defined having body-integrity. This is why, individuals losing visible body parts also loses their normal identity and they are supposed to get used to 'disabled' identity.

Additionally, Senra, Oliveira, Leal, & Vieira (2012) examined the experience of lower limb amputation. Findings revealed that eight themes emerged from interviews: reactions and feelings about becoming amputee; changes in own life; problems in well-being; relation with the prosthesis; self-perceptions; aims related to the rehabilitation and future plans; relation with the rehabilitation; and perceived social support facilitating a theoretical model for the self-identity changes related to limb loss.

In the study of Ward Khan, and colleagues (2019)'s, three superordinate theme emerged which are "I don't like the way I am": changes to relationship with the self, "broken/not wanted": threatened relationships, and "same but different": societal roles by the aid of interpretative phenomenological analysis (IPA) of the woman amputees' body image and sexuality post amputation. It was revealed that female amputees were not compassionate to their novel body image despite their resilience, they experienced the stigma and felt less likely to be desired sexually following amputation.

Furthermore; Miller, Mealer, Cook, So, Morris, and Christiansen (2020) examined resiliency characteristics of unilateral transtibial amputees by using Charney's theory of resilience and Connor-Davidson Resilience Scale scores. Five main resilience characteristics (themes) were identified: coping skills, cognitive flexibility, optimism, skill for facing fear, and social support for amputee sample. Participants with higher resilience scores generally described effective use of coping skills, cognitive flexibility, optimism, skills in facing fears, and social support to attain meaningful goals. In contrast, participants with lower resilience scores discussed passive coping

strategies, cognitive rigidity, general pessimism, avoidance of activities due to fear, or social support limitations.

Moreover, Runyan, Herbert, Knight, Todd, Washington, and Thompson (2022) examined the experiences of combat related amputees of veteran male experiences by using phenomenology. Findings revealed six emergent themes: grief, will to live and fight, amputation adjustment issues, social support as a protective factor, coping skills, and posttraumatic growth. They both pointed the reactions to loss and also resilience of the amputees which might be beneficial for the rehabilitation purposes.

1.3. Traces of Prolonged Grief in Amputees

Medical area is also getting interested in the effects of grief on physical health (Spiess, et al., 2014; Pomeroy, et al., 2020). Lately, amputation experience was given voice by the aid of qualitative studies. Livingstone, and colleagues (2011)'s research focused on experience of diabetes-related amputation which is analyzed by grounded theory method. Data analysis revealed three categories: 'imposed powerlessness' covering the lack of knowledge related to risk of being amputated due to the diabetes, 'adaptive functionality' including responses to physical aspects of the amputation and 'endurance' focusing on the psychological and emotional effects of amputation and adaptation. The endurance theme includes the feelings of loss and grief. However, the grief literature mostly focuses on death and person as a loss. On the other hand, loss of an organ or a limb is also can be grasped as death of an organ and also loss of a both limb, functionality, non-disabled identity with body integrity bringing inevitable grief to process, adjust and adapt psychologically.

Factors affecting psychosocial well-being of patients after limb loss is still an issue scarcely well-understood (Paniagua, et al., 2022). According to Worden (2018), PG is lack of precise diagnosis criteria endanger that the experiences of loss is getting measured by more well-defined pathologies like depression, anxiety, and somatization which can be a part of mourner's experience but not the whole grief experience. Grief processes of losing limb resembles the losing a spouse as regard to sense of shock, denial, numbness, anxiety and depression (Parkes, 1975). On the other hand, Worden (2018,) criticizes both grief researchers and clinicians in terms of failing to grasp

“uniqueness of the grief experience” by pushing it to fit in one diagnose and tailored therapy. There is only one retrospective research that Pomeroy, and colleagues (2020) conducted being subject to prolonged grief of hand amputees that 38% of them had prolonged grief. It was demonstrated that individuals with limb loss and prolonged grief had higher percentages of nociceptive, neurological, and phantom limb pain complaints compared to amputees without complicated grief.

Therefore; the current study is aiming to investigate to prolonged grief experience of amputees is twofolded. In the first study, the relationship among demographics of participants, prolonged grief and perceived phantom pain will be examined. Following the initial results, participants prolonged grief experience will be inquired by the aid of semi-structured interviews for the sake of a better understanding of lived experience of prolonged grief in amputees.

1.4. Aims of the Study

To my knowledge, it was surprising to realize that the relationship between limb loss and prolonged grief is not well-documented. Therefore; this dissertation had explanatory purposes in order to shed light into prolonged grief of amputees. This is why the research was planned to be two-folded using both quantitative and qualitative methods. In the first study, it was aimed to examine the relationship among prolonged grief, psychological symptoms, the association of frequency and intensity of perceived residual and phantom pain and residual pain to prolonged grief of amputees on individuals losing limb. In the second study, it will be examined how prolonged grief is experienced by individuals losing body part(s). Participants to this study was invited in accordance with the prolonged grief scores of the first study.

1.4.1 Research Questions of the Study 1

1. Do amputees have prolonged grief (PG-13)?
2. Which factors might be associated with prolonged grief of amputees?

1.4.1.1. Hypothesis of Study 1

3. There is a positive relationship between prolonged grief and frequency and intensity of perceived residual pain.
4. There is a positive relationship between prolonged grief and frequency and intensity of perceived phantom pain.
5. There is a positive relationship between prolonged grief and depression level?
6. There is a positive relationship between prolonged grief and psychological symptoms (anxiety, depression, negative self, somatization, hostility)?

1.4.2 Research Question of the Study 2

How do amputees experience prolonged grief?

CHAPTER 2

STUDY 1

In Study 1, before examining the PGD of amputees, the construct validity and internal reliability of PG-13 were examined to be able to rely on the instrument's appropriateness of the amputee sample. Explanatory Factor Analysis (EFA) was used as losing limb is quite different than losing loved ones in nature rather than confirming the factor structure of PG-13. Followingly, Cronbach Alfa was examined. Finally, Pearson correlation was used to examine the relationship between demographic and amputation related information and psychological symptoms with PG-13.

2.1 Method

2.1.1 Participants

Data was collected from 103 individuals having loss at least one body limb loss due to varied reasons (medical, traumatic, etc.) after six months post amputation by the aid of inviting them to the online study link prepared in Qualtrics (online data collection software) and from prosthesis center and special permission of Turkish Physical Disability Sport Federation. All in all, 60 (58.3) amputees participated to the study by paper-pencil method which 84 (%81) males consisted of majority of the sample. Amputees' age ranged between 18-74 with a mean of 36.1 (SD = 14.1).

2.1.2 Measurements

2.1.2.1 Demographics

The Demographic Information Form was constituted by the researcher consisting of demographic questions such as age, gender, level of education, socio-economic level,

level of amputation, cause of amputation, perceived frequency and intensity of both residual and phantom pain (see Appendix A).

2.1.2.2 Prolonged Grief Scale (PG-13)

Prigerson and colleagues (2009) proposed a scale composed from the Inventory of Complicated Grief (Prigerson, et al., 1995) including 13 items by considering the most common and accepted symptoms of prolonged grief and also classification systems of DSM-5 and ICD-11. PGS has one dimension and five criteria aiming to diagnose Prolonged Grief Disorder and also to determine the intensity of the symptoms. Eleven of items includes Likert rating (ranged between 1-never to 5-lots of times in a day) and 2 of items have dichotomous choice (yes&no). Participants are expected to rate in 11 items about desiring, missing, yearning, sadness, surprise, shock, role confusion, trouble in accepting the loss, unable to trust others, the sense of unable to move on life, numbness, emptiness and meaninglessness. The other questions focus on evaluating the duration of symptoms and disruption in the social-occupational functionality. Turkish adaptation of the PG-13 was accomplished by Işıklı, et al., (2020) and found to be a valid and reliable. Internal consistency was found to be .90, and one factor structure was confirmed by factor analysis.

Prolonged grief diagnose requires necessarily a loss and disruption in functionality (social, occupational and other areas). Following, separation criterion (question 1 or 2 should be responded at least once a day), time duration criterion (at least 6 months), and cognitive, emotional and behavioral symptoms (from question 4 to 12, at least 5 questions over 9 questions should be responded at least once a day or more) should be met to be able to diagnosed PGD. If the criteria are met, the respondent is suggested to be evaluated by a mental health professional in detail (Işıklı, et al., 2020).

Items of PGS was revised for the current study to be able conduct to the participants having limb loss (See appendix B).

2.1.2.3 Beck Depression Inventory (BDI)

The self-report scale is constituted from 21 items evaluating depression level and risk of adults (Beck, 1961). The inventory's translation and adaptation showed that it is a

reliable and valid scale to use in Turkish population (Hisli, 1989). Increase of the scores indicates the increase in level and risk of depression. Internal reliability (Cronbach Alfa values) was found .95 in this study (see Appendix C).

2.1.2.4. Multidimensional Scale of Perceived Social Support (MS-PSS)

The scale has 12 items evaluating social support of family, friends and significant other was developed by Zimet et al. (1988). The instrument was found to be reliable and valid in Turkish adaptation by Eker and Arkar (1995). The higher scores point out higher level of perceived social support in each area and also in total. Internal reliability (Cronbach Alfa values) was found .92 for total score, and ranged between .89 and .93 for subscales in this study (see Appendix D).

2.1.2.5 Brief Symptom Inventory (BSI)

The scale is a short self-report form composed by Symptom Check List-90-R (SCL-90-R) to evaluate a general psychopathology including 53 items (Derogatis, 1992). BSI is adapted into Turkish and found to be a valid and reliable measurement inventory (Şahin, and Durak, 1994). It has five dimension which are anxiety, depression, negative self, somatization, hostility. Internal reliability (Cronbach Alfa values) of the factors is ranged between .63 and .86 (see Appendix E).

2.1.3 Procedure

First of all, necessary ethical approval was received from Human Participants Ethical Committee at Middle East Technical University. Data was be collected from amputees both online and in orthosis and prosthesis center by using the paper-pencil method voluntarily. Then the raw scores were turned to the numeric data to be able to analyze in SPSS-25.

2.2 Results

Individuals with inborn physical deficits, amputees having limb lost less than 6 months and invalid data were removed from the data. The hypothesis was tested by using the data of 103 amputees.

2.2.1 Descriptive Statistics

Sixty participants participated study by paper-pencil method from orthosis and prosthesis centers, 43 of them was recruited from online data collection method. There were 84 females and 19 males with a mean age of 36.1 (SD = 14.1). Demographic characteristics of the participants were summarized in Table 1 and information about amputation was given in Table 1.

Table 1. *Demographic Variables' Type, Mean, Standard Deviation, Range, Percentages*

Variables	Type	M	SD	Range	N	%
Data collection type	Paper-pencil method				60	58.3
	Online				43	41.7
Gender	Male				84	81.6
	Female				19	18.4
Age		36.1	14.1	18-74		
Relationship Status	Single				43	41.7
	Married				57	55.3
	Other				3	2.9
Residence	Ankara				54	52.4
	Other cities				49	47.6
Education Level	Elementary				14	13.6
	Middle School				4	3.9
	High School				28	27.2
	College Student				15	14.6
	Undergrad Degree				33	32
	Graduate Student & Degree				9	8.8
Working Status	Working				54	52.4
	Unemployed				47	45.6
	Missing				2	1.9
Job change after amputation	Yes				22	21.4
	No				78	75.7
	Missing		3	2.9		
Socio-economic Level	Low				64	68.1
	Middle				18	17.5
<i>Demographic Variables' Type, Mean, Standard Deviation, Range, Percentages</i>						
Variables	Type	M	SD	Range	N	%
Socio-economic Level	High				12	11.7
	Missing	9	8.7			

Table 2. *Information related amputation*

Variables	Type	M	SD	Range	N	%
Number of loss	One limb loss				65	63.1
	Multiple loss				38	36.9
Time since loss		16.3	13.1	6 mont-66 years		
	6 Month – 1 year			11	10.7	
	2 years - 5 years				11	10.7
	6 years - 10 years				12	11.7
	11 years – 20 years				66	64.1
	Missing				3	2.9
Part of loss	Lower leg extremity				48	49.5
	Upper Limb extremity				21	20.4
	Foot				7	6.8
	Arm				10	9.7
	Under hip				3	2.9
	Un-specified				6	5.8
Reason of amputation	Medical reasons				35	34
	Traffic accidents				25	24.3
	Accidents				27	26.2
	Explosions				9	8.7
<i>Information related amputation</i>						
Variables	Type	M	SD	Range	N	%
	Missing				7	6.8
Perceived nature of loss	Unexpected				88	85.4
	Expected				12	11.7
Intensity of residual pain		2.33	2.6	0 – 10		
Frequency of residual pain		2.70	2.68	1 – 8		
Intensity of phantom pain		2.2	2.4	0 – 10		
Frequency of phantom pain		2.7	2.6	1 – 8		
	Intense Pain			19	18.3	
	Slight consistent pain			13	12.6	
	Prickle sensation			30	29.1	
	Tickle sensation			16	15.5	
Precaution	Yes, it could have been prevented				38	36.9
	No				62	60.2
	Missing				3	2.9
Users of Prosthesis					87	84.5
Prosthesis Adaptation	Yes				28	27.2
Rehab Program	Yes				39	37.9
Referral to psy help	Yes				38	39.6
	Psychiatry (Medicine)				29	28.2
	Psychotherapy				19	18.4
	Family Counseling				8	7.8
Benefit of psy help	Yes				43	41.7
	No				32	31.1
	Missing				28	27.2

Table 3. *Mean, Standard Deviations, Obtained Range Scores of Psychological Measures*

Name of Variable	Mean	SD	Range
PG-13 (N = 83)	22.1	9.43	11-48
MS-PSS (N = 81)	64.4	15.0	12 - 84
Romantic	20.2	6.6	4-28
Family	22.5	5.42	4-28
Friends	21.6	5.44	4-28
BDI (N = 68)	19.4	11.8	0 - 45
BSI (N = 45)	67.2	39.3	6 – 173
Anxiety (N = 45)	15.5	8.52	0 – 37
Depression (N = 50)	14.0	11.7	0 – 50
Negative Self (N = 51)	12.6	10.5	0 – 46
Somatization (N = 54)	8.17	6.44	0 – 25
Hostility (N = 54)	7.72	5.24	0 - 22

2.2.2 Findings about Research Questions

First of all, psychometric properties of PG-13 were examined to be able to make reliable inferences for the first research question. Therefore, explanatory factor analysis was conducted and Cronbach Alfa was examined.

2.2.2.1 Factor Structure and Internal Reliability of Turkish form of the PG-13 in Amputee Sample

A Principal Component Analysis (PCA) was performed to determine the factor structure of the PG-13. Varimax rotation was used. The Kaiser–Meyer–Olkin (KMO) value was found to be 0.88. Results of Bartlett’s test for sphericity were found to be $X^2 = 616.87$, $df = 55$ ($p < .001$). The PCA results showed two factors with eigenvalues greater than 1. The first factor had an eigenvalue of 6.26, the second factor had an eigenvalue of 1.2. The first factor explained 56.92 %, and the second factor 10.51%, and also in total 67.43% of the variance. Items 7, 8, 11, 12 double positively loaded to both factors, and similarly, the rest of items loaded both factors and but negatively loaded to second factor. However, all of the items had higher loadings in the first factor. Therefore, one factor solution was considered to be better for this scale on amputee sample. Similarly, one factor structure was determined in the adapted version of Turkish PG-13.

All in all, factor structure was fixed to one factor. The Kaiser–Meyer–Olkin (KMO) value was found to be 0.88. Results of Bartlett’s test for sphericity were found to be $X^2 = 616.87$, $df = 55$ ($p < .001$). Eigenvalue of the factor was of 6.26, and explained 56.92% % of variance. Factor loadings ranged between .61 and .85.

The Cronbach’s alpha value for the 11 items of the PG-13 was found to be 0.92.

2.2.2.2. Examination of PG-13 in Amputee Sample

Twenty-six amputees (25.2%) fit the criteria of PG-13 for referral to psychiatrists. Moreover, 11 amputees (42.5%) had multiple losses. Time since amputation was ranged between 6 months and 31 years with 9.21 mean (SD = 9.73). Furthermore, 96.2% (N = 25) of amputees with possibility with PG diagnosis declared the unexpectancy of loss. Reason of loss was due to medical reasons for %38.5 (N = 10), traffic accidents for 26.9% (N = 7), accidents for 23.2% (N = 6), and explosions for 11.5% (N = 3) of amputees.

Additionally, correlation of PG-13 with other variables was examined to find answers for Research Question 2.

2.2.2.2. Correlation of Demographics and Prolonged Grief-13

Correlation of demographics and amputation related information was given in Table 4. Even though total scores of PG-13 were calculated for examination purposes, possibility of PG was only can be inferred by certain criteria summarized in *instruments section*.

There were a positive correlation between the possibility of PG diagnosis and severity ($r = .25$, $p < .05$) and frequency ($r = .22$, $p < .05$) of residual pain, and also severity ($r = .24$, $p < .05$) and frequency ($r = .25$) of phantom limb pain. Moreover, there were a negative correlation between time since amputation and frequency of both residual ($r = -.29$, $p < .001$) and phantom limb ($r = -.28$, $p < .001$). On the other hand, there was no correlation between possibility of PG diagnosis and perceived nature of loss ($r = -.14$, $p > .05$). Correlation of other demographic variables with PG was depicted in Table 4.

Table 4. *Correlation of Demographic Variables with Prolonged Grief Scale*

	1	2	3	4	5	6	7	8	9	10	11	12
1. T-PG-13	1											
2. PG-13	.52**	1										
3. Age	.10	.10	1									
4. Gender	-.09	.10	.01	1								
5. Marital Status	.04	.02	.57**	-.11	1							
6. Loss Age	.34**	.31**	.65**	.07	.37**	1						
7. Time Pass	-.34**	-.33**	-.28**	-.07	.15	-.56**	1					
8. Intensity of RP	.20	.25*	.12	.07	.22*	.23*	-.18	1				
9. Frequency of RP	.26*	.22*	.06	.19	.27**	.27**	-.28**	.69**	1			
10. Intensity of PP	.09	.24*	.12	.13	.18	.19	-.12	.74**	.53**	1		
11. Frequency of PP	.20	.25*	.12	.07	.16	.32**	-.29**	.58**	.71**	.74**	1	
12. Nature of loss	-.08	-.14	-.07	-.06	.15	-.19	.17	.04	-.12	-.03	-.21*	1

T-PG-13: Total Score of PG-13, PG-13: Possibility of having prolonged grief, * = $p < .05$, ** = $p < .001$

2.2.2.3. Correlation of Psychological Variables and Prolonged Grief-13

None of the psychological variables were correlated with PG-13 summarized in Table 5.

Table 5. *Correlation of Psychological Variables*

	1	2	3	4	5	6	7	8	9	10	11	12	13
1. T-PG-13	1												
2. PG-13	.52**	1											
3. T_SS	-.19	.03	1										
4. T_SS_Fa	-.20	-.03	.89**	1									
5. T_SS_Fr	-.18	.09	.85**	.73**	1								
6. T_SS_R	-.13	.02	.84**	.60**	.51**	1							
7. T_BDI	.04	-.03	-.33**	-.24*	-.17	-.39**	1						
8. T_BSI	.20	.03	-.48**	-.34**	-.23	-.57**	.73**	1					
9. T_BSI_An timer	.22	-.01	-.44**	-.35**	-.22	-.47**	.65**	.94**	1				
10. T_BSI_Dep	.32*	.12	-.45**	-.23	-.31*	-.52**	.64**	.95**	.87**	1			
11. T_BSI_Host	.13	-.08	-.19	-.10	-.03	-.35*	.76**	.87**	.81**	.72**	1		
12. T_BSI_Som	.13	-.06	-.12	.01	.05	-.29*	.74**	.89**	.85**	.74**	.87**	1	
13. T_BSI_NS	.19	.10	-.26	-.12	-.13	-.37**	.75**	.97**	.87**	.93**	.80**	.78**	1

T-PG-13: Total Score of PG-13, PG-13: Possibility of having prolonged grief, T_SS: Total Perceived Social Support, TT_SS_Fa: Total Perceived Social Support_Family Subscale, TT_SS_Fr: Total Perceived Social Support_Friends Subscale, TT_SS_R: Total Perceived Social Support_Romantic Partner Subscale, T_BDI: Total scores of Beck Depression Inventory, T_BSI: Total Score of Brief Symptom Inventory, T_BSI_An timer: Total Score of Brief Symptom Inventory_Anxiety Subscale, T_BSI_Dep: Total Score of Brief Symptom Inventory_Depression Subscale, T_BSI_Host: Total Score of Brief Symptom Inventory_Hostility Subscale, T_BSI_Som: Total Score of Brief Symptom Inventory_Somatization Subscale, T_BSI_NS: Total Score of Brief Symptom Inventory_Negatif Self Subscale, * : $p < .05$, ** = $p < .001$.

2.2.2.4. Testing the Hypothesis

To conclude, Hypothesis 1 and 2 were failed to reject according to correlation analysis. There is a positive correlation between PG-13 and both frequency and intensity of residual and phantom limb pain. However, Hypothesis 3 and 4 were rejected which was there were no correlation between PG-13 and depression levels and psychological symptoms of amputees.

In conclusion, individuals with limb loss might have prolonged grief and PG-13 can be a reliable and valid measurement for amputee sample. Additionally, residual pain and phantom limb pain was found to be associated with prolonged grief. On the other hand, perceived unexpectancy of amputation might be another factor might be associated with prolonged grief.

CHAPTER 3

STUDY 2

As grief experience is peculiar to each individual's personal history, former traumas and loss experiences, and capacity to process grief, social environment and the culture; each amputee experience the loss of body part very unique. When multiple losses of amputees and changes are taken into consideration such as; loss of body part(s), body integrity, "normal" (normative) body appearance, "normal" identity and also adaptation to absence of body part(s), prosthesis, wheel chair, disability identity, etc., which brings multiple and simultaneous grief processes at the same time. It might be regarded as each individual experiences this complex process on their own way. This is why, prolonged grief experience of amputees had better to be accomplished by qualitative methods to be able to investigate this specific phenomenon. Qualitative research is required to be able understand the meaning of events and things in dept (Lune & Berg, 2017). As prolonged grief of amputees is a phenomenon that lived experience is not clearly defined and understood, Interpretative Phenomenological Analysis (IPA) was chosen as an appropriate tool to analyze the data that usually is subjected to everyday life experiences at least particular significance in individual's lives (Smith, Flowers, & Larkin, 2022).

According to Smith (2004), IPA is an idiographic (i.e., detailed analysis of each case), inductive (i.e., bottom-up analysis) and interrogative (i.e., integrated with the literature) method aiming to explore the respondents' personal experiences in a particular way and how they give meaning to their experiences. IPA attempts to get 'experience close' by acknowledging the impossibility of finding a direct path to experience for those having this 'experience far'(Smith, 2011). Furthermore, IPA can be explained as giving a voice to the respondents' concerns from the eye of the researchers (Larkin, Watts, & Clifton, 2006). As IPA includes two worldviews of both

respondents and also researchers, it is conducted in a double hermeneutic way; in which the researchers interpret the world of the respondents (Smith, 2011). Smith (2004) defined IPA as a tool that initiates the curiosity of researchers and gives them a starting point helping them to begin with an understanding of the experience.

Although IPA was initially designed to be used in health psychology, such as; patient's illness experience and psychological distress (Smith, 2011). Currently, it is used to analyze a different range of experiences including but not limited to emotions (Aldridge, Fisher, & Laidshaw, 2019), attitudes toward addiction (Fricker, Banbury, & Visick, 2018). Growing literature of IPA brings the necessity of guidelines for the level of specificity in terms of quality of the papers and on the judgment of the authors (Nizza, Farr, & Smith, 2021). After Smith (2011a, 2011b)'s initial attempts for ground of the good IPA, Nizza, Farr, and Smith (2021) revealed much more detailed three quality levels of as good, acceptable and unacceptable by evaluating the published IPA papers in years between 1996 and 2008 from the Web of Science, Medline, and Psycinfo databases. *Good IPA should be keeping focused and offering depth, presenting strong data and interpretation, and engaging and enlightening the reader.* These criteria were taken into consideration in the whole parts of the IPA research.

3.1 Method

3.1.1 Participants

Participants of this study recruited by the aid of contact numbers of volunteer amputees participating in the Study 1. Respondents both with and without prolonged grief were included to the study as Smith et al. (2022) suggested that not only the ones experiencing the phenomenon but also both parts of a phenomenon facilitate a better understanding. For instance, including therapists and patients to an IPA research can be example in order to understand the therapy relationship phenomenon. The sample of this IPA included 3 amputees with prolonged grief, and 3 amputees without prolonged grief. Participants met the criteria which are being amputated at least 6 months ago and the most 10 years ago, being at least 18 years old, and being singular leg amputation. It is planned to reach the participants by the aid of social media. As the number of female volunteer participants in Study 1 were limited and the ones who

attended were not eager to be a part of Study 2, one female participant who did not meet the being singular leg amputation was involved to the sample to be able to give the female voice to the research. All in all, 6 respondents were recruited to the interviews. Demographic features of sample is in the *Table X*. The sample size will be congruent with the IPA guidelines if it is 6 up to 10 participants. As IPA is an intensive and detailed analysis of cases, small and homogeneous samples were preferred (Smith & Osborn, 2003).

3.1.2 Procedure and Data Analysis

Initially, ethical approval for the study was received from the Human Subjects Ethics Committee of METU. Semi-structured interviews were conducted (see Appendix F). As demographics is already taken in the first study, each interview began with the introductory questions like who they were. Following this warm up, the story of amputation and the meaning of amputation for them (i.e. what do you think this happened to you?) was interrogated. The researcher transcribed the interviews verbatim. Each interview was listened, re-read carefully, and notes were taken descriptively to be able to unite those notes into themes. The procedure was repeated for each case separately in order to cluster the initial themes (Smith, Flowers, & Larkin, 2009). IPA facilitated to the emergence of the superordinate themes and sub-themes regarding the transcripts. Interviews lasted between 53 to 98 minutes. Demographics of the respondents were given in Table 6.

3.1.2.1 Trustworthiness of the Study

In qualitative research, credibility and trustworthiness issues are arising as the researchers' point of view might affect the analysis of the uncooked data. Different than the quantitative research, qualitative research acknowledges the researcher bias as an inevitable subjective nature of conducting research (Morrow, 2005). From the scope of qualitative research, subjectivity of the researcher(s) contributes to the quality of studies by the aid of experiential insight. This is why, reflexivity of the researcher facilitates to understand better sense-making process from the researcher's point of view (Patton, 2002). Trustworthiness of the study can be guaranteed by the aid of reflective bracketing that the possible effect of researcher's personal suppositions is

framed in advance (Gearing, 2003). Here is my bracketing below in terms of my academic and practitioner life.

The author (I) of this dissertation was a practitioner clinical psychologist in psychoanalytic training and also familiar with cognitive-behavioral, schema and systemic approach, and academically interested in relationship between soma and psychology and disadvantaged groups due to abnormality. Even though there is no visible disability of the researcher, she has witnessed that stigma and discrimination to the individuals with mental disorder is an issue being suffered from in Turkey in addition to the sufferings of emotional burden of it. Moreover, grief is a topic that Freud and his followers are prone to give importance in their clinical practice and a theoretical area which was becoming a diagnose attracting attention in the last decades in the mainstream mental health area. Therefore, she was willing to listen and give voice to the lived experience of this minority group of people which their rehabilitation was mostly based on physical adjustment to their novel conditions.

Table 6 .*Demographics of Respondents of IPA*

	Gender	Relationship status	Education Level	Age	Time elapsed	Type of amputation	Reason of amputation	PG-13	Psychological help
Participant 1: Yağmur	Female	Married with 2 children	High School	32	22 months	Single above amputation	Aggressive Fibromatosis (relapse)	Yes	Yes
Participant 2: Neriman	Female	(Married) with 1 child Separated	High School	33	18 months	Double below knees & double hand fingers amputation	Scleroderma + Raynaud's Disease + vascular disease = necrosis	Yes	Yes
Participant 3: Gürol	Male	Married with 2 children	High School	41	9 months	Single below knee amputation	Vascular Disease = necrosis	Yes	No
Participant 4: Erdem	Male	Single	University Student	24	18 months	Single below knee amputation	Birth defect and risk of sclerosis	No	No
Participant 5: Sabri	Male	Married	Elementary	45	9 months	Single below knee amputation	Traffic accident	No	No
Participant 6: Sadık	Male	Engaged	Bachelor	30	9 years	Single above knee amputation	Bone and soft tissue cancer	No	No

3.2. Findings of IPA

Four superordinate themes were emerged which are: 1) life & death or amputation has two subordinate themes which are *surviving with the cost of limb loss, and the test in life*, 2) absence of limb, 3) holding on life and 4) still there.

3.2.1. Life & Death or Amputation

This superordinate theme emphasizes that the meaning to the amputation which stands in between life and death. It has two subordinate themes which are *surviving with the cost of limb loss, and the test in life*. Decision of amputation can often be seen as a forced choice to be able to survive at a time when death is at stake especially in health-related problems rather than accidents and explosions. While this choice is sometimes suggested and deemed as necessary by a doctor, sometimes it can also be having to face with a loss that has already occurred. But now, even though the amputation has displaced death on the stage, it stays in the foreground for a while by disrupting the usual order of life.

3.2.1.1 Surviving with the Cost of Losing Limb

This subordinate theme includes the conditions bringing amputation and saying goodbye to their limb. At some point, between death and life, amputation and giving up on the limb become necessary due to excruciating pain and dysfunction or difficulties of the limb. Five participants, except Sabri, gave the obligatory decision of letting their limb cut off due to risky health problems. This farewell, which will bring new bodily boundaries, also a healthier body and closer choice to life than death. But the price lies in giving up on it especially for those having health related problems for amputation.

For Sadık, he desired the least damage when he first began his cancer treatment at the age 21, he faced with his relapse and spread of his cancer after 8-month treatment and kneecap surgery. Sadık, who had a prosthesis on his kneecap after receiving chemotherapy, learned that the cancer had spread to the soft tissue during his follow-ups and accepted to be amputated in the same day it was proposed by his doctor. He mentioned that he got scared from the spread pace of cancer in 1.5 months due to his young age which facilitates his decision of amputation to be able to survive. During

this time, his decision to give up on his leg crystallized due to that he experienced a lot of pain and witnessed death of other patients in hospitalization process, pace of his cancer spread.

When I woke up in the morning, I saw that the patient lying next to me had passed away. It has been a very difficult process. It wasn't easy..... you are at a point between death and life..... I always have a question mark in my mind. There are questions that I wonder if I will get well or whether I die like one of these patients in my mind. Because you don't know. You have time ahead of you. You don't know what time will show, what it will bring, how much of the chemotherapy given and how the body will respond..... I have lost a limb that we spent 20 years together which I have realized eventually that it was an important part of mine..... My leg witnessed many things until it got amputated. Of course, to lose it, to feel its absence, to know that it will never come back was just as how one feels when a person dies. (Sadık, 30, public officer)

Original: Sabah kalktığım zaman yanımda yatan hastanın vefat ettiğini de gördüm. Çok zor bir süreç oldu. Kolay olmadı..... yani ölümlerle yaşam arasında bir noktadasınız..... Aklımda hep bir soru işareti var. Acaba ben de iyileşecek miyim yoksa bu hastalardan biri gibi yani vefat edip gidicek miyim gibi sorular var yani. Çünkü bilemiyorsunuz. Önünüzde bir zaman var. Zamanın ne göstereceğini, neler getireceğini, verilen kemoterapinin ne kadarına vücut nasıl cevap vereceğini bilemiyorsunuz.....20 yıl boyunca benimle beraber gelen, benim önemli bir parçam olduğunu anlamama sebep olan bir uzvumu kaybettim Çok büyük olaylara şahit oldu benim bacağı ampütasyon olana kadar. Tabi ki onu kaybetmek onun yokluğunu hissetmek onun bir daha geri gelmeyeceğini bilmek ki nasıl bir insan vefat edince onlar oluyorsa bende de onlar oldu

Sadık experienced that even though he was willing to give up on his leg, there is no guarantee that he will survive from this illness. The ambiguity he experienced and his choice to survive was also related his bonds with life and the price that he is willing to live even if giving up on his leg was necessary. Gürol also mentioned about his sudden hospitalization process after he went to the hospital for his complaint about cold hand problem. Followingly, he suffered from huge amount of pain which were unhealed scars and immobilized foot (almost paralyzed) following angio conducted to him despite the strongest painkillers, morphine, for 3.5 years before the amputation. The suffer was so intense and chronic that amputation suggestion might be heard as savior that the decision was taken like “(Dedim gözünüzü kırpmadan alabilirsiniz)”, “you can take it (the foot) without blink (hesitation).” When the price was clear to pay to the death, meaning and importance of what was giving up on was also evaluated for

the last time. Irreversibility of the lost and loss of walking long hours are the parts that dropped from a lively life.

When we decided to have my foot removed, I said goodbye to my foot 5 minutes before the doctors started the preparation. You have served me until now. You served my understanding, at the point of knowing God better, I said thank you very much, let your serves be halal and we left our feet. (Gürol, 41, unemployed)

Original: Ayağımın alınmasına karar verdiğimizde hocalar hazırlığa başlamadan 5 dakika önce ben ayağımla vedalaştım. Bugüne kadar bana hizmet ettin. Benim idrakıma hizmet ettin allahı tanımam noktasında dedim çok teşekkür ediyorum hakkını helal et dedim ve helalleşerek ayrıldık ayağımızdan.

Even though there are things given up but also there is appreciation of what was taken so far for Gürol. For him, his leg was reminder of God's generosity. On the other side, the pain, and the suffering and also death threat facilitates the decision of farewell to the limb. Similarly, Neriman had three different life-threatening diagnosis which she suffered from extreme pain in her hands and feet dragged her into the decision of amputation. Her condition was so serious that her illnesses rise she was transferred to another hospital in another city to be treated which did not work. However, as she was not well-informed about that her operations would be performed by local anesthesia, she sounded she was so shocked when learned the conditions of her operation and could not think of to say goodbye to her appendages. Her amputation was traumatic and rememberable separation than the other participants in which she was awake during in all her amputation surgery which might contribute her current psychological disturbance.

The pain of the cut from the surgery was nothing. The pain I had before was much, much more. Something happened to me in the surgery, I felt that I was saved. Or it was psychological..... I already admitted that I lost my hands and feet while I was in the hospital, before I left there. If I don't accept that, you don't want a rotten limb, you don't want one who can't walk. You don't want a painful limb. So I had to accept it. I didn't want them, I didn't want the things in my life that made my life difficult, so I don't want them. (Neriman, 33, housewife).

Original: Ameliyattaki kesik acısı hiçbir şeydi. Öncesinde yaşadığım ağrılar çok çok daha fazlaydı. Ameliyatta şey geldi bana, kurtulduğumu hissettim. Ya da psikolojikti. Ellerim, ayaklarımı kaybetiğimi çoktan kabul ettim hastanedeyken, çıkmadan önce. Kabullenmesem, çürümüş bir uzuv istemezsiniz, yürüyemeyen istemezsiniz. Acı veren bir uzuv istemezsiniz.

Mecburen de kabullendim yani. Ben onları istemedim hayatımda benim hayatımı zorlaştıran şeyleri istemedim, istemiyorum yani.

Neriman already gave up on her limb psychologically before she physically lost them due to her non-stoppable pain. For her, amputation was a closure to endless pain for her. Interestingly, she started to feel relief and felt less pain than her former suffering during the operation as she already gave up on her unfunctional and painful appendices. On the other hand, Yağmur had many ups and downs and hesitations during the time she decided to amputation due to her rare but fast progressing tumors. Doctors had variant opinions about her situation. This is why she had hesitations for decision of amputation and also hopeful to get healed with various treatments. She narrated that she calculated the disadvantages of keeping her leg that they were constantly going to emergency due to her pain and coming back to home numb. Moreover, she faced with the danger of dying if the benign tumors spreads to the waist and becomes malign which did not work all of them eventually. She declared that she had psychological support from a profession even for her treatment due to her hospital fear before amputation and after amputation.

After I found out that my leg was going to be amputated, I became very bad. I had no appetite, I could not eat, I could not sleep. You know, you always look into space without thinking about anything. Because you don't know what will happenBesides, if it (the tumor) goes higher, it would be more dangerous. If it goes to the hip, it can turn from benign to bad right now. That fear made me think it's better for my leg to go.... I accepted....At least my pain has gone. But my leg has gone too..... Although I was bad when I thought it would be cut, I started not thinking about it. The day of surgery came, I said goodbye to my leg. I drew a lot of pictures and wrote (laughing) texts on them. (Yağmur, 32, housewife)

Original: Bacağımın kesileceğini öğrendikten sonra ben çok kötü oldum. Ne iştah kaldı yemek yiyebildim, ne uyuyabildim. Hani hep boşluğa bakarsın ya bişi düşünmeden. Ne olacağını bilmiyorsun çünkü.....Hem daha yukarı çıkarsa (tümör) o daha tehlikeli olacaktı. Kalçama çıkarsa, şu an iyi huylu kötüye çevirebilir. O korku bacağımın gitmesi daha iyi diye düşündü.... Kabul ettim....En azından ağrılarım gitti. Bacağım da gitti ama..... Her ne kadar kesileceğini düşündüğümde kötü olsam da düşünmemeye başladım. Ameliyat günü geldi, bacağımla vedalaştım. Bir sürü resimler çizdim üstüne (gülerek) yazılar yazdım.

As the amputation was an ambiguous solution to get away from tumors and the possibility of death. She has no regret that she accepted to get amputation to get rid

her constant pain in her leg despite of the strongest painkillers, and to be with her kids as a mother. However, it was difficult for her to face with absence of her leg after surgery despite of all horrifying consequences to keep it. From another point, the functionality and threat to the health also might be a reason for amputation. Erdem is an amputee football player, had the risk of scoliosis because of uneven length of his legs and was pleased about his decision. He chose to cut his leg off to be able to use more functional prosthesis and also to get rid of his less functional leg. He focuses on the advantages of his limb loss. It won't be wrong to say that he lightened up almost inborn burden leg of him to gain pace and healthier body posture in life according to his words. This might symbolize his getting rid of his inborn disability and taking control over his life by deciding the proportion of loss.

In terms of being able to use a prosthesis, and being more useful in football. I was unable to use a prosthesis. I had a prosthesis made. I was having difficulty getting in and out of the car with my old prosthesis. Now I have no difficulties. It facilitated me that way. In the second aspect, my mother said, for example, it was a part of you, how did you do it, and she was amazed. And I said mom, there's nothing you can do. I told my mother that if something doesn't work for you, you're going to cut it out..... There were difficulties in football as well. For example, the longer the limb, the more difficult it is in our (amputee) football. It is a fault when the ball touches his missing limb. My hand counts. The longer the limb, the more negative it becomes. So my shortcut had a positive effect on me. It'll be faster as well. Minus. How can I say? Also in terms of weight. There must be an estimated 750 grams of my limb. As a result, I lost weight. An object moves faster when weight decreases. I am thinking about her. (Erdem, 24, University Student)

Original: Protez kullanabilmek açısından, bir de futbolda da daha yararlı olabilmesi açısından.....Protez kullanamıyordum. Protez yaptırđım. En azından eski protezimle arabaya inerken binerken zorluk yaşıyordum. Şimdi hiç zorluk yaşamıyorum. O yönden kolay oldu. İkinci yönden de hani annem mesela şey dedi, senin bir parçandı nasıl yaptın falan dedi hayret etti. Ben de dedim anne yapacak bir şey yok. Bir şey sana yaramıyorsa kesip atacaksın gibi bir şey demiştim anneme Hem futbolda da zorluk oluyordu. Mesela uzuv ne kadar uzun olursa bizim futbolda o kadar zor oluyor. Eksik uzvuna top değince faul oluyor. Elim sayılıyor. Uzuv ne kadar uzun olursa o kadar negatif oluyor. O yüzden benim kestirmem pozitif yönde etki etti bana. Hem daha hızlı olur. Eksi. Nasıl deyim. Kilo açısından da. Kesilen uzuv nerden baksan 750 gram vardır tahminen. Sonuç olarak kilo azaltdı bende yani. Kilo azaldığı zaman bir nesne daha hızlı olur. Onu düşünüyorum.

Erdem not only gained physical pace but also the psychological pace for not being inhibited from the idea that he carries a dysfunctional leg inborn. Different than Erdem,

Sabri has no right to choose amputation as he already lost his foot before he was hospitalized after the traffic accident. He was not psychologically ready to say goodbye to his foot. Additionally, he was reluctant to mention his 1-year hospitalization period and mentions about how he feels and coped with his loss by using religious beliefs. He sounded distant to his feelings, and he was unwilling to give details and talk about his inner world as it was given by God.

I do not mind. I am not a person who cares a lot. No, it happened like that. I've never been. I have trouble traveling by myself. My foot hurts when I walk too much, but there is nothing to do. It came from God. We'll be grateful and sit down (Sabri, 45, longroad driver)

Original: Hiç kafama takmadım. Takan bir insan değilim ben. Yok öyle oldu böyle oldu. Ben hiç valla. Kendim gezmekte sıkıntı çekiyorum. Ayağım ağrıyor fazla yürüyünce falan ama yapacak bir şey yok. Allaha geldi. Şükredip oturcaz

Different than all participants, Sabri was not involved in the decision process. His only decision can be adaptation to his new conditions or to collapse with it. He declared that his easy-going personality and his belief helped him to accept his and cope with his limb loss.

Five participants were willing to pay the cost of their limb for the sake of getting rid of their excessive amount of suffering and decrease the possibility of death or losing their healthy status which makes their life hard to bear. At the time of giving the decision of amputation, amount of pain experienced, witnessing death, and decaying of their limb and considering the ones left behind directed them to make their decision certain. Losing limb were not only getting rid of the pain, and death but also meant peace, reminder of having it and its memoire. Despite the legitimacy of reasons to be amputated, the obligatory cost was so staggering to be accepted easily and would have been experienced post amputation which requires time to face with the eality of what was lost and how to accept the abstinence.

3.2.1.2. The Test in Life

After amputation was accomplished, the life was divided into two periods sharply as before and after which requires a meaning to be able to keep going on life. Therefore,

this subordinate theme focuses on meanings given to the amputation which is a test given by God to try loyalty and dedication of their belief in God or their ties with life.

For instance, Neriman thinks that what happens to her is her exam in life given by God to test the sincerity of her beliefs in God. She puts herself in a position as if a chosen messenger strengthens her faith instead of rebelling because of her lack of means for people to be grateful for their lives. In this way, she gets into a closer relationship with God by creating a special position for herself by not breaking his relationship with God having complaints, doubt, critics or questioning to her destiny or faith. She takes strength from her religious beliefs by using a shelter, asking for patience rather than getting angry or offended. She protects herself from her destructive and rebellion thoughts and behaviors in this way of thinking.

I believe that my creed helped me a lot in that process. In God's way, if I did not have such faith, maybe I would have been a rebel, but I was not a rebel. I didn't say anything. I didn't say why it happened to me. I said Lord, I asked for patience, I asked for mercy, I didn't say anything else.....I say it is my test. I'm not saying why it happened to me. Everyone has a reason to exist in this world.....The purpose of my test in this world is clear. I was born into this world, but now people who know me can thank themselves due to me when they see me.... Think about it, being a reason to be thankful for someone is also a great blessing. I didn't complain about that, it's not a lie (Neriman, 33, housewife)

Original: O süreçte o itikatımın bana çok yardımcı destekçi olduğuna inanıyorum. Allahın o yolda eğer böyle itikatım inancım olmasaydı belki asi olcaktım ama asi olmadım. Şey demedim. Niye benim başıma geldi demedim. Yarabbi dedim sabır dedim merhamet dedim başka bir şey demedim.....Sınav diyorum. Neden benim başıma geldi demiyorum. Bu dünyada herkesin varoluş sebebi var.....Benim de bu dünyadaki sınavımın amacı belli. Ben bu dünyaya geldim ama şu anda beni tanıyan insanlar kendi hallerine benim adıma şükredebiliyorlar beni gördüklerinde.....Düşünsene biri için şükür sebebi olabilmek de çok büyük bir nimet. O konuda şikayette bulunmadım hani, yalan değil

Neriman gives meaning to her limb loss which others might get benefit to be able to feel gratitude about their wholeness. Therefore, her loss of limb turned to be a reason for her to be a messenger given by God like Gürol. Sabri also mentions that this is a test for himself and his belief. He mentioned that he did not complain to anyone about his condition, and that he lay quietly and rested while he was sure that others would have been writhing in pain. Thus, it is not rebellion to God who rebels in this test by

keeping their experiences inside and not complaining about his situation. Similarly, Sadık is believing this is his own test in life. He is trying to calm himself by reading the Quran and reading his words in this test of Allah.

Human beings go through a test when they are born. This is clearly obvious in the Qur'an. There are certain tests in life. This is totally my test. My test in this world. And God is watching how I will respond to them. He's observing how I approach things. I'm not a person who likes to swear at all. Shall I blaspheme against Allah?..... Will I accept that as a test that God gave me or will I be rebel? These always came to my mind. I always thought this way. And in fact, the biggest factor that rehabilitated me during these periods is the Quran. I was reading every day and I really felt a sense of peace while reading it. I was trying to pray as much as I could. I still continue to do as much as I can. I think this way. After that, the questions why I started to go away from me.... I had been supposed to experience. I accept in my mind that I had to pass this exam and that's why I lived it. (Sadık, 30, public officer)

Original: İnsanoğlu dünyaya gelirken bir sınavdan geçiyor. İşte çünkü bu Kuranı Kerim'de de apaçık belli. Belli imtihanlar oluyor hayatta. Bu da tamamen benim imtihanım. Benim bu dünyadaki sınavım. Bu da allah benim bunlara nasıl cevap vereceğimi gözlemliyor. Olaylara nasıl yaklaşacağımı gözlemliyor. Bu olay yaşandıktan sonra acaba çok affedersiniz hiç küfretmeyi seven bir insan değilim zaten. Allaha şirk koşup küfür mü edicem?..... isyan mı edicem ya da onun vermiş olduğu bir imtihan olup eyvallah deyip kabullenmeye mi çalışıcım. Hep bunlar geldi benim aklıma. Hep bu yönde düşündüm. Ve benim aslında bu yaşadığım dönemler içerisinde beni rehabilite eden en büyük etken Kuranı Kerim. Her gün okuyordum ve okurken gerçekten bir huzuru hissediyordum. Elimden geldiği kadar namazımı kılmaya çalışıyordum. Halen de elimden geldiğince yapmaya devam ediyorum. Öyle düşünüyorum. Ondan sonra zaten niye ben soruları gitmeye başladı bende.... Benim yaşamam gerekiyormuş. Benim bu sınavdan geçmem gerekiyormuş ve o yüzden yaşadım diye benimsiyorum aklımda.

Sadık used his belief both as a protecting shield from the disturbing feelings and questions about his amputation necessity, life and his existence and coping mechanism to sooth himself. On the other hand, although Erdem is congenitally disabled, he was amputated due to better prosthetic use and the risk of scoliosis and back slippage. Erdem is against the idea that being born with a disability and being amputated is a test with religious meanings. Before amputation, he questions his life and his body and thinks about giving up on his life due to his existential crisis one morning. Eventually, he decides to take responsibility of his life, internalizing a realistic point of view and not depending on God, inborn and external factors.

I would have thought the same thing, even if it was later. And because it is congenital....I got out of bed and I just stepped on the ground and it occurred to me that I don't have a foot. I saw that I had no feet. I sat and thought for 10-15 minutes. I said there are 8 billion people. Why me among 8 billion people? I entered such an existential state. I started questioning myself. It's a different situation. I said here, why do things like this find me? I thought why me? That day may be a turning point for me..... Is it possible for a person to take the exam incomplete? Can they enter without half of the exam paper? For example, we take an exam. In normal life, there is an exam, I gave you 20 questions and 30 questions for you. Is there such a thing.... Some thoughts confuse me. So I can think the opposite in that direction. I don't think this is a test either. The shortcoming has happened to you. You will either live or you will live. You will accept it and live with it or you will be offended by life. Or you will choose the difficult one. There is such a thing, the facts of life. The important thing is to achieve the difficult... to continue life.... (Erdem, 24, university student)

Original: Sonradan olsaydı da gene aynı şeyi düşünürdüm. Doğuştan olduğu için de....Yataktan kalktım tam yere bascam ayağımın olmadığı aklıma geldi. Ayağımın olmadığını gördüm. Oturdum bir 10-15 dakika düşündüm. Dedim 8 milyar insan var. 8 milyar insan içinde niye ben. Öyle bir varoluşsal bir hale girdim. Kendi kendime sorgulamaya başladım. Değişik bir hal. İşte dedim niye böyle şeyler beni buluyor. Neden ben diye düşünmüştüm. O gün bir dönüm noktası olabilir benim için..... Sınava 1 kişi eksik girebiliyor mu? Sınav kağıdının yarısı olmadan girebiliyor mu? Sınav oluyoruz mesela. Normal hayatta sınav oluyor sana 20 soru verdim sana da 30 tane. Öyle bir şey var mı yok.... Bazı düşünceler kafamı karıştırıyor. Yani o yönde zıt düşünebiliyorum ben. Bu da bir sınav değil bence. Eksiklik sana denk gelmiş. Sen de ya yaşayacaksın ya yaşayacaksın. Bunu kabullenip yaşayacaksın ya da hayata küseceksin. Ya da zor olanı seçeceksin yani. Böyle bir şey var, hayatın gerçekleri. Önemli olan zoru başarmak... hayata devam etmek.

At the end of his existential inquiries, it seems that Erdem clings to himself that he should take care of his life by accepting the inequalities in life, instead of rebelling and being embittered, and, taking strength from this collapse and questioning, he continued his life with a realistic view of life.

Five participants attributed a religious meaning to their amputation and used their belief to feel special and important and as a coping mechanism to relief their anger and rebellion feelings. However, Erdem rejected the idea that this is his test given by a God or universe which facilitated to find his inner locus of control. As amputation is such a challenging life event that amputees require an omnipotent figure which might provide a meaning to their unfair situation which they had to say good-bye to their body parts. All in all, losing a body part a shaking life event to face with and handle to process and digest both psychologically and physically which might direct amputees

to question the meaning of life, the order in life and role of one in life. As the religions and spirituality provides answers about the life, amputees tried to benefit from it after this compelling life situation. They mostly preferred not to question why this happened to especially them and throw the ball to the faith to protect their good inner relationship with God.

3.2.2. Absence of the Limb: “The Life Becomes Upside Down”

Amputation brings many concrete and abstract losses and changes in amputee’s lives at once. This is why this superordinate theme focuses on the losses in addition to the limb loss which includes job loss, marriage and spouse loss, loss of function and normal person identity and gaining new identity with disability and loss of wholeness; and intense/ambivalent feelings including incompetence, missing, anger, rejection and denial.

Although the necessity of amputation has been considered, especially for reasons such as health problems; the possibility of amputation or disability is not an expected possibility by default. Maybe it just pops up when they are in denial that human beings are fragile creatures which can be broken easily and makes their life upside down without any preparation.

Yağmur never thought of having an identity with disability one day in her life and she both suffered from her disease, moving to other cities to make her diagnosis clear, being away from home and her children and sudden irreversible changes in her life making her life upside down which causes mood swings and sudden anger outburst to her family. And she sadly admits that she reflected her sense of incompetency to the ones that she loves with sudden and undesired anger outbursts. She confesses that she misses her leg like she lost someone she loved. In addition to missing her limb, she felt frustrated about the irreversibility of her loss.

They get hit by a car, for example, they can amputate both legs. I never thought that I would be disabled too. Everything was fine in my life. My life was turned upside down in an instant. I spend my whole life in the hospital. You feel nervous all the time. It affects my whole life. I am at war with myself. I argue a lot with my husband. It is the same with my kids. Because it is very difficult to deal with the disease... .. It's been very ups and downs. One day or two days I am very happy. My walking is smooth. I'm pretty good. The next day, my leg

will go wrong, my walking will go wrong. I'm out of mood right away. I don't want to go outside. I can even shout loudly at my children sometimes. I am very against violence, but I can shout too much. Because I'm nervous....that's the way it is. Three days like that, two days like that. There is no such stability.... Sometimes there is such a longing. You know, when you miss someone you know, like your mother you're your father when you don't see them, you want to hug them, but it feels like missing a different person. It was like she was someone and really left. Something happens like I am missing..... At first, one never thinks of these things. This happened 2-3 times in 1.5 years. My friends ask, are you in pain or in a bad mood? I say I miss my leg. They tell me that longing is not like that. You can't miss. No, I was saying that I really miss you. I wish you were next to me so we could walk normally. You know, as they always say to console, it will pass. It does not go away (angrily). It will not pass. My leg will never come back here again. (Yağmur, 32, housewife)

Original: Araba çarpıyor mesela iki bacağını ampüte edebiliyorlar. Benim de engelli olacağım hiç aklıma gelmezdi. Hayatımda her şey yolundaydı. Hayatım bir anda tepetaklak oldu. Tüm hayatım hastanede geçiyor. Geriliyorsun. Tüm yaşantımı da etkiliyor. Kendimle savaşa giriyorum. Eşimle çok tartışıyorum. Çocuklarımla öyle. Çünkü hastalıkla uğraşmak çok zor..... Çok inişli çıkışlı oldu. Bir gün iki gün çok mutluymumdur. Yürüyüşüm düzgündür. Gayet iyiyimdir. Ertesi gün bacağımda terslik olur, yürüyüşümde bozukluk olur. Hemen keyfim kaçar. Dışarıya çıkmak istemem. Çocuklarıma karşı bile bazen çok bağırabiliyorum. Şiddete çok karşıyım ama bağırımlarım fazla olabiliyor. Çünkü gerginim..... O şekil oluyor. Üç gün öyle iki gün böyle. Bir gün öyle bir gün böyle sabitlik yok.... Bazen öyle bir özlem geliyor ki. Hani sanki tanıdık birini, anneni babanı görmediğin zaman özlersin ya sarılmak istersin ama öyle sanki farklı biriymiş gibi geliyor. Hani sanki biriydi ve gerçekten gitti. Özlüyorum gibi bir şey oluyor..... İnsanın ilk başta hiç aklına gelmiyor bunlar. 2-3 kere oldu bu 1.5 yıl içerisinde. Noldu ağrın mı var, moralin mi bozuk diyor arkadaşlarım. Diyorum ki bacağımı özledim. Özleme öyle olmaz diyorlar bana. Özleyemezsin. Yok gerçekten özlüyorum diyordum. Keşke yanımda olsaydın, normal yürüyebilseydik.... hani hep teselli etmek için derler ya, geçecek. Geçmiyor geçmiyor (öfkeyle). Geçmeyecek ki. Benim burdan yeniden bacağım çıkmayacak.

Yağmur attributed changes in her life to her illness can only be partially true as amputation was stemmed from her health condition. Albeit, as treatment had been successful, there would be no need for giving up on her leg. She was hesitant to put the center to the amputation which she was struggling to adapt with as she was not even prepared to the idea of losing it. Even if she chose to be amputated, losing the limb was an unexpected incident for her in life. She carries intense amount of ambivalent feelings at the same time resulted in undesired outbursts time to time. Similarly, Neriman misses her feet and feeling the sands in the seaside under her feet and the way she puts her rings on finger. As she lost her husband in her illness and

amputation process, missing her rings might symbolize the times she had them all, both her fingers and the husband. She also pointed out sense of desperate due to the irreversibility of her losses.

I love the sea very much. I love it extremely. For example, I love to walk barefoot by the sea. In other words, I am a sea sick lady, I am a person who really loves the sea. And I live in a city near a seaside, and that's how I grew up. If I go to the seaside now, for example, I say to the girls, take off your feet for me and walk... You don't know the value of somethings until you experience their loss. Do you yearn, you do but have nothing to do (Neriman, 33, housewife)

Original: ben denizi çok severim. Aşırı derecede çok severim. Mesela deniz kenarında yalınayak yürümeyi çok severim. Yani deniz hastası bayanım gerçekten denizi çok seven bir insanım. Ve deniz olan bir memlekette yaşıyorum, öyle de büyüdüm. Şimdi deniz kenarına gitsem mesela kızlara diyorum ki benim için ayaklarınızı çıkarın yürüyün..... Kaybını yaşamadan bilemiyorsun bazı şeylerin kıymetini. Özlem duyuyor musun, duyuyorsun ama yapacak bir şeyin yok

Additionally, before going to the military duty, Sadık worked in the construction sector for 2 years, 1 year in abroad. However, during his military service, he was diagnosed with bone cancer and had a left upper leg amputation. As a result, the fact that he could not return to his job back. He describes this period “ *the times that becoming turning point of my life*”(*Sonra hayatımın dönüm noktası olan zamanlara gittim yani*”). His life was divided into two as pre and post amputation not due to his cancer diagnosis but because of his amputation followed by his cancer diagnosis and its relapse which requires many changes with it. When the reality hit that he was no longer able to live the pre-amputation life’s job, he worked hard to the exam of civil servant for people with disability (E-KPSS). He was quite aware of losing the capabilities that he had such as; the loss of stepping, and standing with two legs, perpetuating his walking ability. He declared that one need to be more careful both with crutches and prosthesis to protect themselves. Sadık had to face with the new challenges in life post amputation not just losing his current job and his financial independency but also necessity to adaptation to novel limits of his physical capacity. Similarly, Sabri complained about his loss of function about endurance of his walking capacity. Sabri lost his lifestyle which he likes walking around, wandering around and lost his car, house due to financial problems post amputation. Sabri could not go back to his occupation after the accident, and he had financial shortage due to his limb loss.

The car is gone too..... Whatever I have in my hands..... I had a house, I had a car, I had everything. Now we live in a rental....We can't do anything. I walk 100m 200m daily. I can't lift, I can't bring, I can't take. I can not do anything. I can't keep my balance..... Where would I not go? I would go to the seaside. We would go on a picnic, I would never stop. I used to travel. I couldn't stand still. I'm that type of person. So you can't hold me. But now I get tired after walking a bit, it hurts. I need to rest after a little walk. (Sabri, 45, longroad driver)

Original: Araba da gitti..... Elde avuçta ne varsa..... evim vardı, arabam vardı, her şeyim vardı. Şimdi kirada oturuyoruz....Hiçbir şey yapamıyoruz. Günlük 100m 200m yürüyorum. Yük kaldıramıyorum, getiremiyorum, götürmemiyorum. Bir şey yapamıyorum. Dengemi sağlayamıyorum..... nerelere gitmezdim ki. Giderdim denize girerdim. Pikniğe giderdik, hiç durmazdım. Gezerdim de gezerdim. Yerimde duramazdım. Ben öyle bir tipim. Tutamazsın beni yani. Ama şimdi biraz yürüyünce yoruluyorum, ağrı yapıyor. Biraz yürüyünce dinlenmem gerekiyor

Even Sabri started to function after recovery, he still misses the lifestyle that he had before amputation and was unpleasant about the new limits of his body anymore. Yağmur was one of the participants having intense amount of ambivalent feelings. She feels disappointed about her current pace, her changed body about conducting daily chores and the need to get helped about those and feels like being burden and supported at the same time. She suffers psychologically so much that she wishes to have her limb back almost to feel like having it and facing the reality again that it has gone which gives her more sadness and disappointment. She also feels hopeless and will always be needy to the others about when she focused on irreversibility of losing her capabilities as if she lost her independence and her body strength.

everything slows down. What I can do right away doesn't happen right away anymore. I used to clean in one hour. Now you are vacuuming in a room, it takes me 1 hour. Because I'm tired. I have to sit and rest all the time. You are so slow even at that, you go backwards in everything. Compared to normals, you are behind 3-0, not 1-0, you are behind, so that much. Because sometimes you can't wear your leg. It gets swollen sometimes. You can't always wear it. Or sometimes you just don't wear it. Even if you do, it is already slow though..... It feels terrible when you can't do. My hands are sound, I am sane, I am healthy, I exist, I am standing. But you cannot do everything. It's like it's a burden to someone else. I can not. I can't get enough. I can't reach. Sometimes it's envy, too. When I look at people who have children outside. They walk normally, but I can't do it at the same speed.....I got very furious when they walk normally, because they were going too fast (laughing) (Yagmur, 32, housewife)

Original: *her şeye daha çok yavaşlıyor. Hemen yapabildiğim bir şey hemen olmuyor. Eskiden 1 saate temizleyip çıkıyordum. Şimdi bir odada süpüyorsun benim 1 saatimi alıyor. Çünkü yoruluyorum. Sürekli oturup dinlenmem gerekiyor. Onda bile çok yavaşsın, her şeyde geri geri gidiyorsun. Normallere göre 3-0 geride kalıyorsun 1-0 değil geride kalıyorsun yani o kadar fazla. Çünkü bacağımı bazen takamıyorsun. Bazen şiş oluyor. Her zaman takamıyorsun. Ya da bazen canın takmak istemiyor. Taksan da zaten yavaş Yapamadığı zamanlar insana çok fazla koyuyor. Ellerim sağlam, aklım yerinde, sağlıklıyım, varım, ayaktayım. Ama yapamıyorsun her şeyi. Yani başkasına yük oluyor gibi. Yapamıyorum. Yetemiyorum. Yetişemiyorum. Bazen özenti de oluyor. Hani çocuğu olanlara baktığım zaman falan. Dışarda. Normal şekilde yürüyüp gidiyorlar ama ben aynı hızda yapamıyorum.....normal gidilince çok sinirim bozuluyordu, çok hızlı gidiyorlar diye (gülerek)*

Even Yağmur accepted that she lost her leg, she had problems with losing her pace in daily life when compared herself with “*normal people*” and also losing her motherhood and resentful the need for her prosthesis or crutches and being have to slow down. She feels invaded by her sense of incompetence that forces herself to act like post amputation by not being careful enough not to fall because of the *carpet or a sock on the floor*. She was struggling with accepting that small and simple details might turn to be disaster for her in new life. Similarly, Erdem realized the differences between being inborn handicapped and being amputated. Before amputation, he was able to use his underdeveloped leg to step and for daily chores; however, he lost its function post amputation which he needed his crutches or prosthesis to have *simple a cup of tea for himself*.

On the other hand, participants mentioned how people started to look at them and that their aesthetic concerns elevated due to loss of wholeness. For instance, Yağmur was having hard time to give meaning what she is experiencing about the changes in her body and had an ambivalent attitude towards the way her look aesthetically which she needed one more amputation due to the spread of tumor during the time interview conducted.

It is also very bad in terms of appearance (laughs). Too bad even now. It's worse not to have any. I can't make much sense of that. Very weird. I will see it too. I will understand how. I can't find answer while think of it. I never paid any attention to the image. It gets on my nerves sometimes (laughs). My clothes don't suit me. It looks so ugly. It looks out of proportion, it's getting on my nerves. The suit you made up, now looks so ugly when you wear it that you

don't want to wear it again. When you look at it, it doesn't seem appropriate at all. (Yağmur, 32, housewife)

Original: Görüntü itibari ile de çok kötü (güler). Şu an bile çok kötü. Hiç olmaması daha kötü. Böyle çok fazla anlam veremiyorum. Çok değişik. Onu da görücem. Nasıl olduğunu anlayacağım. Düşüne düşünemiyorum. Görüntüye hiç önem vermedim. Bazen sinirimi bozuyor (güler). Giydiğim kıyafetler yakışmıyor. Çok çirkin duruyor. Orantısız duruyor, sinirimi bozuyor. Alt üst uydurduğun takım şimdi giyince o kadar çirkin duruyor ki üstünde bazen böyle insan onu bir daha giymek istemiyor. Baktığın zaman hiç uygun gelmiyor.

She was in between not caring for how she looks and a sense of ugliness. She most probably feels gratitude to survive but also ungrateful to remember to lose her wholeness at the same time. However, Erdem was glad that he decreased his aesthetic concerns in his look.

Good thing I did. It is a limb that is both bad in terms of appearance and ridiculous. The feet are at knee level. I was stepping on this foot, so I'm glad I had a cut (amputation). I am neither missing nor sad. Good thing it's gone. (Laughs). I had it for a while, but in the end, this is better in terms of both appearance and prosthesis as vital life. (Erdem, 24, university student)

Original: İyi ki kestirmişim. Hem görüntü açısından kötü, hem saçma sapan bir uzuv yani. Ayağı dizin hizasında. O ayağa basıyor, yani iyi ki kestirmişim diyorum. Ne özlüyorum, ne üzülüyorum. İyi ki gitmiş. (güler). Bir ara vardı ama sonuçta hem görünüm açısından hem hayati yaşam olarak protez açısından bu daha iyi.

In addition to aesthetic concerns, Neriman was abandoned by her husband in her illness process. While Neriman was struggling for her life against the joint effects of 3 different diseases, she was transferred to a hospital in another city, which has more advanced facilities than her hometown, for better treatment opportunities. However, her husband rarely visited her, brought their child during the treatment period. Separated from both her home and her child, Neriman also suffered from a loss of her marriage. She now lives with her child at the house of her origin family. Not only the city she lived in, but also the family environment has changed, and now she was struggling with the uncertainty of custody as the divorce process continues. Additionally, her husband started a new relationship during this period made her devastated.

What I'm not going through is that, as a result, the family that I know as my family, my order has deteriorated... We got married happily and we didn't have any marital problems. When did I fall to the hospital? He said that even if I get better and return home, he will not enter the house, he said that he will not return Previously, when there was no disease, there was no problem, but when there is a disease, everything turned upside down and changed upside down. After all, you are broken, so you are worn out. Didn't this process wear me out? But whether I am better, I hope that I am better..... After the amputation, my husband and I broke up anyway. I was abandoned..... He could take care of me if his parents accepted, but not if his parents didn't accept me. Even if you come back, we will not have a relationship except for the child. Now I realized that our path had come to the point of separation, even if it was difficult, I thought that our paths should be separated and I filed for divorce. We are currently in the divorce phase. (Neriman, 33, housewife)

Original: Neler yaşamıyorum ki sonuç olarak psikolojik olarak aile bildiğim, aile düzenim bozuldu..... severek evlendik ve ailesel bir problemimiz yoktu. Ben ne zamanki hastaneye düştüm. Ben iyileşsem de eve dönsen de o eve girmeyeceğini söyledi, dönmeyeceğini söyledi Daha önceleri hastalık yokken hiçbir problem yokken hastalık olunca her şey altüst olmuş, tepetaklak değişmiş yani. Sonuçta kırılıyorsun, yıpranıyorsun yani. Bu süreç de beni yıpratmadı mı yıprattı. Ama düzeldim mi düzeldim diye umut ediyorum..... Ampüte olduktan sonra eşimle ayrıldık zaten. Terk edildim..... Annesi babası Kabul ederse beni bakabileceğini, annesi babası kabul etmezse bakamayacağını. Sen geri dönsen de çocuk haricinde ilişkimiz olmayacağını. Ben de artık yolumuzun zor da olsa ayrılma noktasına geldiğini fark ettim, yolumuzun ayrılması gerektiğini düşündüm ve boşanma davası açtım. Şu anda boşanma evresindeyiz.

Neriman believed in that she was laid aside and rejected by her husband post amputation. She lost her relationship status in society as a married woman even if she was not willing to break-up or end her marriage as if she would no longer be able to be a housewife and a wife being attractive with body integrity. While she was looking after her family and their relationship was going on, she was abandoned that she became the one requiring to be looked after. Similarly, Sadık experienced a divorce post amputation. He thinks his divorce was *more unfair and traumatic* than his amputation. He felt disappointed as he was let down and had hard time due to his additional loss. Being rejected by their spouses might decrease their self-esteem and trust the people especially in close relationships after they lost their body integrity. Moreover, being rejected and unwanted in his illness and post amputation process by his extended family was another hardship and a loss for Gürol.

At this point, if you are asking about my root family, people also seem to have fallen into a void. At that moment, it was my life lesson, and maybe their tests too. A distant was occurred.... They did not completely turn their backs. I'm talking about my root family. God bless them. I mean, my wife's family. My wife's brother, my mother, father, brother and sister. Of course, they may have had problems with their own lives in the life..... The result of the psychological state I was in started to feel like I was a burden to them. I had a rosy life before. Everyone was enemshed. All of a sudden, everyone started to contradict each other. Everyone moved away from each other. And the material was very active in it. The material dimension was very influential. Here's my wife's family from my family's financial situation is at a limited point. This was probably the biggest reason for those cold distances. Here we cannot do anything at the material point. There is an expectation, there is a negative material dimension that we suddenly fall into. And they can't support us at that point. At least we should stay away so that the thoughts of the moment do not rise. Don't let their thoughts raise their troubled thoughts. Because of this, they moved away. (Gürol, 41, unemployed)

Original: Bu noktada birinci derecede ailemi soruyorsanız, insanlar da bir anda boşluğa düşmüş gibi oldular. O anda benim hayat dersim de belki onların da öyleydi. Bir uzaklaşma oldu..... Tamamen sırt çevirmediler. Birinci derecede ailemden bahsediyorum. Allah razı olsun. Yani eşimin ailesi. Eşimin kardeşi, annem babam abim ablam. Bunlar tabi ki hayatta kendi hayatları ile ilgili sıkıntıları olmuş olabilir İşte içine düştüğüm psikolojik durumun sonucu onlara yükümü gibi gelmeye başladı. Daha öncesinde güllük gülistanlık bir hayatım var. Herkes içli dışlı. Bir anda herkes birbiriyle ters düşmeye başladı. Herkes birbirinden uzaklaştı. Bir de bunun içerisinde madde çok etkendi. Maddesel boyut çok etkendi. İşte kendi eşimin ailesinden benim ailemin maddi durumları sınırlı noktada olduğu için. Bizi çok büyük ihtimal o soğuk uzaklaşmaların en büyük sebebi buydu. İşte biz şey yapamıyoruz maddi noktada. Bir beklenti var bir anda bi içine düştüğümüz olumsuz maddi boyut var. Ve o noktada bize destek olamıyorlar. Hiç olmazsa biz uzakta duralım ki o andaki şeyleri yükselmesin. Düşünceleri sıkıntılı düşünceleri yükselmesin. Bundan kaynaklı uzaklaştılar.

Gürol felt rejected by his foot family in the initial years of his illness due to his financial scarcity and expected more psychological support from his family. However, as his and his wife's extended families had limited budgets for their own, they have created distance made him felt rejected and abandoned by them. While his life was getting fall apart by losing his health, job, economical independence; he also felt disappointed by the distance of his extended family like the crew leaving the sinking boat. From another point of view, after 9 years, Sadık sounded like he gave a meaning to what he is going through due to his amputee. Even though he lost his wholeness in the eyes of his relatives and the society; he realized that he was also not familiar with amputees in his environment despite of pity stares of the others. And he sees this

process as a two-way street for both amputees and the society to get used to which he sounds peaceful about the looks and himself.

A relative of ours had come to visit. I always say that it carried a good intention. because they feel sorry for me, because they love me. She cried when she saw me. I was very impressed then..... Even though we unwillingly prepare ourselves for that situation, when we see such a reaction, they make me feel as if my situation is very bad, that I am in a very difficult situation. I was also unintentionally impressed. I didn't want any visitors in the first week, 10 days. I didn't want anyone to visit except my family... I could understand very well that they were upset when they looked. I sensed it right away, but over time they got used to it. Because I have never seen amputees around me. In fact, I am the first person with amputation in the region where I live..... This also helped them to understand more that we are special people to be welcomed as normal. Today, instead of looking with pity, for example, I hear proud words. (Sadık, 30, public officer)

Original: Bir yakınımız ziyarete gelmişti. Ben iyi niyetinden olduğunu zaten her zaman söylüyorum. bana üzüldükleri, sevdikleri için. Beni görünce mesela ağlamıştı. Ben çok etkilenmişim o zaman. ister istemez her ne kadar kendimizi o duruma hazırlasak da böyle bir tepki gördüğümüz zaman sanki durumumun çok kötü olduğunu, çok zor durumda olduğumu hissettiriyorlar. Ben de ister istemez etkilenmişim. İlk 1 hafta 10 gün hiç istemedim. Ailem dışında kimsenin gelmesini istemedim..... Baktıkları zaman üzüldüklerini çok iyi anlıyordum. Hemen seziyordum ama zamanla onlar da alışmaya başladı. Çünkü ben çevremde hiç ampüte insan görmedim. Hatta benim yaşadığım bölgede ilk ampütasyonlu insan benim..... onlar da artık normal karşılanmaya özel insan olduğumuzu daha çok anlamalarına vesile oldu. Hani acıyarak bakmaktansa ben bugün mesela gurur duyulan sözler duyuyorum.

Sadık began to give meaning after years of post-amputation by being empathetic to others' stares as an ordinary reaction to minorities. However, unlike Sadık, Erdem was getting angry with eyes of the others and stigmatization and discrimination eventhough he was disabled before, he became visible with crutches post amputation. He sounded like he lost his invisibility in society and he was not fond of the overcompensatory pity behaviors of the others.

I got on the last bus recently. I had with my prosthesis. A couples approached. Paired. Her husband was with her, and they were standing next to me. The young man said, will you give me a seat? After that, I looked them, they were neither old nor pregnant. Able both. I can understand if there is a condition. I also showed my prosthesis. I showed it. Look, I said I have a prosthesis. The man looked away, as if he didn't say anything. When I showed it like that, when he saw the prosthesis, his look changed to me. While he was looking normally, he suddenly started to look different..... We took the subway. We're going to

work out again. We are with crutches. The subway was jammed, so even the standing ones were full. We were also standing. Then the man next to us said, I will find a place for you, stop. He went and said to those sitting, will you get up? Did not your see there are handicapped ones? He said, do you see that there is a handicapped person? This is something. He embarrassed us. Why do you say that after all? You say that out of all the people. Everyone looked at us this time.....I wish I hadn't gotten on it. I wish I wasn't an individual with disability. I wish I hadn't heard that word, I said to myself. So we're ashamed. If you're doing something, come and ask brother, sit down, give me a place or something. There is an appropriate language, there is a normal language. there is to tell and there is to tell. (Erdem, 24, university student)

Original: geçen otobüse bindim. Egoya bindim mesela. Protez vardı. İki tane bir çift geldi. Eşli. Kocası da var yanında ondan sonra ayakta kaldı. Genç, yer verir misin dedi. Ondan sonra baktım ne yaşlı ne hamile. Sapasağlam ikisi de. Hani bir durumu olsa anlarım. Protezi gösterdim ben de. Açtım gösterdim. Bak protez var dedim. Adam başka yere baktı sanki bir şey demedi. Böyle gösterince hani protezi gösterince bakışı değişti ama bana sanki. Hani normal bakarken bir anda değişik bakmaya başladı.....Metroya bindik. Antrenmana gidiyoruz yine. Kanedyenleyiz. Sıkıştı metro, ayakta kiler bile doluydu yani. Biz de ayaktaydık. Sonra yanımdaki adam dedi ki ben size yer bulcam durun dedi. Gitti oturanlara dedi kalkar mısınız? Sakat var görmüyon mu dedi? Özürlü var görmüyon mu dedi. Bu da bir şey. Utandırdı bizi. Niye öyle diyon ki sonuçta. O kadar kişi içinde bunu diyorsun. Herkes bize baktı bu sefer.....Keşke binmeseydim. Keşke engelli olmasaydım. Keşke bu lafi duymasaydım dedim kendi kendime. Utandık yani. bir şey yapıyorsan da gel kardeşim otur, yer verir misin falan. Uygun dille anlatmak var, normal dille anlatmak var. anlatmak var anlatmak var yani.

However, Gürol, and Yağmur perceived loss of wholeness in the eyes of others different than Erdem. Erdem is the only one among participants having an identity with disability inborn before amputation. Surprisingly, he perceives the stares and words of people in the most hostile way, maybe he is the one being exposed to this stigmatization and labeling to people with disability more years than the others. Contrarily, Gürol was glad that people are being empathic to his trouble and demonstrated him to their *extreme sadness (içlerinin acıdığını görüyorum)* and also *normality (insanlar da alışmış artık, normal karşılıyorlar)* that he was in. Similarly, Yağmur observed that there are people being respectful and helpful for her and also staring at her absent leg.

I see they don't even look down you know not to make me feel sorry. Because I look at people's faces to see if they really look at me like that. While walking, you feel something when you are walking outside with sticks or something, it's like everyone is looking at me, it's weird like that. It's like they're pitying... The

people outside are very curious, they're looking. They stare at my leg like that, and they look at me in a way that make me uncomfortable. I didn't make rubber legs. It looks like iron. I said if I know, everyone should know. Because there are many people who want to look like legs, those who have veneer. They're covering the outside with a sponge. It looks like a leg from the outside.....I chose it that way, after all, I know I don't have a leg, so I said why would I need to hide it. What happens if someone from the outside sees it? I walk unsteadily when my gait is heavy. I wonder why people look at me and walk like that, instead of looking at them strangely, they should look at my leg and not look at my face. Let's at least bring the perception down (laughs)..... people have some respect for it. (Yağmur, 32, housewife)

Original: yok hani üzülürüm, çekinirim diye. Aşağıya bile bakmadıklarını görüyorum. Çünkü insanların yüzüne bakıyorum gerçekten hani böyle bana tuhaf bakıyorlar mı diye. Yürürken değneklerle falan dışarda yürürken şey hissi geliyor sanki herkes bana bakıyor böyle tuhaf tuhaf. Acıyorlar gibi....Dışardaki insan çok meraklı onlar bakıyorlar. Bacağıma gözünü dikiyorlar bööyle bakıyorlar rahatsız edecek şekilde de bakıyorlar. Ben kauçuk bacak yaptırmadım. Demir olarak görünüyor. Dedim ki ben biliyorsam herkes bilsin. Çünkü bacak gibi görülmesini isteyenler çok fazla, kaplama yaptıranlar. Dışa sünger kaplatıyorlar. Dışardan bacak gibi görünüyor.....Ben böyle tercih ettim sonuçta ben biliyorum bacağımın olmadığını neden saklama gereği duyayım ki dedim. Dışardan biri baktığında görse ne olur ki? Yürüyüşüm bollaştığı zaman dengesiz yürüyorum. İnsanlar bakıp niye böyle yürüyor ki acaba derse tuhaf tuhaf bakacaklarına bacağıma baksınlar, yüzüme bakmasınlar. En azından algıyı aşağıya çekelim (güler)..... biraz da insanların buna saygısı var. (Yağmur, 32, housewife)

Even if there is an option for her prosthesis to look more like a leg rather than a stick leg; she chose to be seen as an excuse for different way of walking outside as if like show of defiance. She interpreted that people were not looking down as a respect was a facilitator of perceiving others helpful and empathic rather than stigmatizing and discriminating. On the contrary, she had an extra effort to attract the attention to the down not to be judged as a weirdly walking individual with body integrity. She sounded like she had a desire to be judged by her own conditions as she already had a pressure to be congruent with the society norms. For Neriman, it was a reason to feel proud and competent about not being seen as an individual with disability by others.

They are not even aware (that I am with a disability). Because I continue my normal life. They say we don't matter when I ask. They say that none of us can see you as a person with disability. Because you provide for everything for yourself, you do not demand anything, you meet your own needs. They say we don't see it when I ask. I don't know if it's not a lie (laughs). (Neriman, 33, housewife)

Original: *Farkında bile değiller yani (engelli olduğumun). Çünkü normal yaşantıma devam ediyorum ya. Biz fark etmiyoruz diyorlar sorduğumda. Engelli olarak hiçbirimiz göremiyoruz seni diyorlar. Çünkü her şeyi karşılıyorsun, bir şey talep etmiyorsun, kendi ihtiyaçlarını karşılıyorsun. Biz görmüyoruz diyorlar sorduğumda. Yalan değilse bilmiyorum (gülür).*

From a different point of view, Sabri lost his foot after a traffic accident while he was working as a long-road driver and faced with the reality of losing his current job which he loves to work and using the advantages of his occupation. During the interview, he claimed that limb loss did not affect him psychologically as he was durable enough to stand this hardship while eventually, he confessed that he collapsed when he learned that he lost his foot and he might lose his job due to unable to drive bus anymore. He does not see any point to complaint about his situation due to his feelings of desperateness; thus he sounded like he coped with his hardship by denying those hardships and reality of his suffering like an insane person. He makes himself stop to cry and direct her anger towards the others.

So I'm not affected. What can we do?. There is nothing to be affected. I'm driving myself all to madness. Instead of being smart and suffering the world, be crazy and let the world put up the all trouble. That's why I do not care. For example, I have a lot of pain. I come home and go to bed. So I never raise my voice. For example, my wife's tooth hurts. She speaks 3 times a day about it. I'm not like that. What if I tell her, what if I don't. I don't do anything in my head. I keep it inside me, it goes away. If there was someone else in my place, I don't know they can be burden to the others. I never do anything like that. (Sabri, 45, longroad driver)

Original: *Etkilenmiyom yani. Napcaz. Etkilencek bir şey yok. Hepsini deliliğe vurduruyorum. Akıllı olup dünyanın kahrını çekeceğine deli ol dünya senin kahrını çeksin. Onun için kafama göre takılıyorum. Mesela yeri geliyor çok ağrım oluyor. Eve gelir yatarım. Hiç sesimi çıkarmam yani. Mesela eşimin dışı ağrır. Günde 3 kere konuşur. Ben öyle değilim. Ki onu da anlatsam ne anlatmasam ne. kafamda şeyapmam. İçimde tutarım gider o. benim yerimde başkası olsa oooo ağlamalar sızlamalar ne bileyim. Ona buna yüklenmeler. Ben hiç öyle bir şey yapmıyorum.*

Similarly, Gürol sounded like in denial about psychological disturbance of losing his leg, his job by claiming he got through the whole process very healthy. He split himself into two and projects his rebel to Seytan by choosing to be the one being grateful about his life. However, he denies that he owns his body and consequently his limb loss. This is why it sounds like there is nothing to grieve about.

I looked at my foot, which was amputated like this. I said, Lord, I said thank you endlessly. At that time, they say that my mind is delusional due to the demon. And the mind said to me that you have taken your feet instead of that you will be upset about it you become grateful and thankful. In response to this question, I said, "Why should I be sad about the loss of something that does not belong to me?" At that moment, I really understood that the foot does not belong to us, the body does not belong to us..... the loss of a foot that I thought belonged to me before, and the loss is not a loss either. I still feel my leg right now. Sometimes you say phantom pain, sometimes you say about the amputee. But believe me, I can feel my feet under the ground alive right now. Sometimes my feet itch, I throw my hand away in the amputated part. I really know that it is there and waiting for me. I am feeling. How is this realization, this is a truth in inner thought! When you tell this to a normal person, he sees it as crazy nonsense. Could it be such nonsense? The body, the soul leaves the body, enters the ground, it is known as inanimate, God also commands it.....At this point, I don't see it as a loss. At the moment, in the physical cognitive dimension, I cannot take a step without a stick. If I can open the door, one can even walk in thought without feet. (Gurol, 45, unemployed)

Original: Ayağıma baktım böyle ampüte olan ayağıma. Dedim ki yarabbim sana sonsuz şükürler olsun dedim. O ara zihnim şeytan vesvese veriyor derler ya. Ve zihin bana dedi ki senin ayağın alınmış buna isyan edeceğin üzülceğin yere sen şükür ediyon bu nasıl iştir diye bana sordu. Bu sorunun karşılığında ben de dedim ki bana ait olmayan bir şeyin kaybına ben neden üzüleyim. O an gerçekten anladım ki ayak bize ait değil, vücut bize ait değil..... aynen öncesinde bana ait olduğunu sandığım bir ayağın kaybı ve kayıp da şöyle kayıp da değil. Şu anda hala bacağımı ben hissediyorum. Yeri geliyor fantom ağrısı mı dersiniz, yeri geliyor ampüteyle ilgili dersiniz. Ama inanın ki şu anda canlı şekilde toprağın altında ayağımı hissediyorum. Bazen kaşınıyor ayağım, elimi atıyorum. Ampüte olan kısımda. gerçekten onun orda olduğunu ve beni beklediğini biliyorum. Hissediyorum. Bu idrak nasıl, bu deruni düşünce içindeki bir hakikat. Bunu normal bir insana anlatınca deli saçması olarak görüyor. Böyle bir saçmalık olabilir mi? Vücut ruh bedenden çıkıyor toprağa giriyor eeee o cansız olarak biliniyor ya normalde hakikat da de allah da onu buyuruyor.....Bu noktada ben bunu bir kayıp olarak görmüyorum. Şu anda fiziksel idrak boyutta ben değneksiz adım atamıyorum. Kapıyı açabilirsem düşünce içerisinde insan ayaksız dahi yürüyebilir.

In addition to those, loss of trust is another recurrent issue in the interviews. As the doctors gave them the bad news and at the same time could not predict the treatment and the disease, doctors can only be seen authorities of this tragedy. Trying to find the best referral can be difficult. Incurable diseases destroyed the trust in doctors. It's as if the bills for the pain suffered were made to the doctors. In addition to mistrust to doctors, losing trust to the government and handicapped politics can be another ambivalent feeling.

Gürol was accusing the doctors of maltreating him and directs his accusations to the doctors as he used his faith to cope with his situation. He sounded like distorted the reality that even if he was the one looking for a treatment and a possible diagnose for his cold hands, he misinterpreted the tests done to him (angio) like an enemy attack with some sort of poison to his body by the doctors desiring to earn money from lots of people around him.

I had to leave the hospital with a wheelchair, which I entered by pedestrian. After that, they said get well soon and took me out of the hospital. And our disease process started after that day. I lost my walking 85-90% and the hospital process started... saying that there is a clot in the blood. But at that time, they did the same after me with the same lie to everyone. I went to the hospital and they put me to bed. After that period, I saw that around 50 people in my circle had this problem due to this disease and they were amputated. Some of them died. In short, I won't take too long to say, they did research in the internal medicine department for 1 month. They never told us which drugs they give in the serum. One month later, they performed an inguinal angiography. (Gurol, 45, unemployed)

Original: Yürüyerek girdiğim hastaneden tekerlekli sandalye ile çıkmak zorunda kaldım. Ondan sonra bana geçmiş olsun dediler ve çıkarttılar hastaneden. Ve bizim hastalık süreci o günden sonra başladı. Ben % 85-90 yürüyüşümü kaybettim ve hastane süreci başladı... kanda pıhtılaşma var diyerekten. Ama o dönemde herkese aynı yalanla benden sonra da aynılarını yaptılar. ben hastaneye gittim beni yatırdılar. O dönemden sonra benim çevremde 50'ye yakın bu rahatsızlıktan kaynaklı insanın bu sıkıntıya girdiğini gördüm ve ampute oldu. İçlerinden ölenler oldu. Velhasıl diyeceğim fazla uzatmayım ben 1 ay boyunca iç hastalıkları bölümünde araştırma yaptılar. Hangi ilaçları serumun içinde veriyorlar hiçbir şekilde bize söylemediler. 1 ay sonra kasıktan anjiyo yaptılar.

He was so insecure about the outside world that he declared that he did not want to work again. He and his family was getting supported by his family and local municipality financially post amputation. The psychological collapse that he experienced was serious post amputation that he sounded like he couldn't find the internal power to work for a proper job for his novel condition to gain his economic independence which can be expected from a responsible adult. In the diagnoses and treatment process, Yağmur sounded like she lost her trust to the doctors due to various opinions and sudden decision changes about her amputation. She had experienced that the tumor grew which was said that it would not grow. It is hard to discriminate whether the ambiguous treatment or doctors changing calls caused her fluctuated

moods and loss of trust. Moreover, she lost her trust to the government due to misleading and disappointing positive discrimination politics against the population with disability for her. All in all, she sounded like she lost her reliance to the authorities post amputation

I had a 50% disability report, now it will change. they are forcing these people with disability so much that nothing is as they show. It promises you a house with pink shutters. It says this is yours. But it is not. It's just a tent when you get close (laughs). And you're trying very hard to get that tent. they made everything so difficult..... You go there, it doesn't work. You're going somewhere, no. They say I will not interfere. It's just a recipe. I have a sample recipe; you will write it down. They say I can't do that. This is the doctor. I'm in a wheelchair, why do you torture me? It doesn't work, it doesn't give me anything. They say there is a disability pension. It doesn't suit me. There is a house cleaning service. Even though I do the cleaning so hard, they come 1-2 times a month. It doesn't suit to me. Because there is a car registered with us, it cannot be visited. They look at very silly things as if the car is going to clean the house. They say because you have a registered car on you. Or you can't take advantage of anything. They always set an excuse, a ridiculous rule. What if there was an insured employee at home? What if there is no insured employee at home? What you give me is not enough. They asked such absurd questions that not to help the disabled, but to hinder them.... That's why I got on my nerves and got depressed. What they say and what they do are never the same. So annoying..... (Yağmur, 32, housewife)

Original: %50 engelliyim raporum vardı şimdi değişecek. bu engellilere var ya o kadar çok zorluyorlar ki gösterdikleri gibi değil hiçbir şey. Sana pembe panjurlu ev vaad ediyor. Burası senin diyor. Ama değil. Yanına yaklaştığında sadece bir çadır (güler). Ve o çadırı almak için de çok uğraşıyorsun. her şeyi o kadar zorlaştırmışlar..... Oraya gidiyorsun olmuyor. Buraya gidiyorsun olmuyor. Ben karışmam diyor. Sadece bir reçete. Elimde reçete örneği var bunu yazacaksınız. Diyor ki ben bunu yapamam. Kaçınıcı bu doktor. Tekerlekli sandalyedeyim neden işkence ediyorsun?..... Engelliye bir öncelik falan yok hepsi yalan..... Hiçbir işe yaramıyor ki, bana hiçbir şey vermiyor. Engelli maaşı var diyor. Bana uymuyor. Evde temizlik hizmeti var. Temizliği bu kadar zor yapmama rağmen geldikleri ayda 1-2'dir. Bana gelmiyor. Çünkü üzerimize kayıtlı bir araba olduğu için gelinmiyor. Sanki araba evi temizlicecekmiş gibi çok saçma şeylere bakılıyor. Üzerinizde kayıtlı araba olduğu için diyorlar. Ya hiçbir şeyden yararlanamıyorsun. Hep bir bahane, saçma kural koymuşlar. Neymiş evde sigortalı çalışan varmış. Ya evde sigortalı çalışan olmazsa ben napıcam. Bana senin verdiğin yetmez. Öyle saçma sorular sormuş ki engelliye yardım olmak değil, engel olsun diye..... O yüzden de sinirlerim bozuldu moralim bozuldu. Söyledikleri ve yaptıkları asla aynı değil. Çok sinir bozucu.....

She did not believe in the sincerity of legal regulations were for the sake of population with disability. She witnessed the face of authorities to the individual with disability

post amputation. Also, Sabri proposed not to trust doctors who predicted that he would not be able to walk and drive at least the next two years as he succeeded to be able to be in traffic in 6 months post amputation. On the other hand, Sadık was grateful to his doctor and his support during the all process. Similarly, even though Erdem was required to the second amputation after the first one, he sounded like he did not lose his trust to the doctors. All in all, Yağmur's and Sabri's feelings of anger and desperateness about being amputated irreversibly which cannot be directed to God and to the others being around in Sabri's case might be directed to the doctors and governmental figures.

To sum up, in addition to the concrete losses such as; loss of capability, job and spouse and marriage, loss of perceived support of loved ones, touch with the reality and internal world and trust can be the abstract additional losses to the limb loss. As amputation brings many changes in one's life at a time, intense and ambivalent feelings spill over in many aspects of life from romantic relationships to authority figures.

3.2.3. Holding on Life

This superordinate theme includes the factors facilitating to the adaptation and the changes in the life of amputees to be able to holding on their lives which are adaptation to the prosthesis, spiritual enlightenment, new occupation, developing new relationships and improved relationships by being supported, new hobbies, improved self-concept and changes in world concept.

All the participants declared that they adjusted the use of prosthesis even if it was hard in the beginning. Doctors propose to use prosthesis at least after 6 months from the surgery to give time for healing of residual scar/pain. Learning how to walk with the prosthesis can be beginning of their new life like a newborn baby and holding on life begins with a substitute leg to be able to walk and function as much as possible likewise before amputation.

Erdem stated that adjusting lack of leg followed is the first step to adjust the prosthesis. Prosthesis use requires new skills to step up, control the knee and walking in bumpy roads. Being obliged to adjust to the prosthesis is a source of motivation for him to regain independence in his life.

At first, I thought I had a foot and I felt like I can step on it, but since I didn't know I didn't have a foot, it's not a problem for me anymore. My new prosthesis is also not the same as the old prosthesis as it is an upper limb prosthesis. I had the difficulty for 1 year because I needed to check its knee as well. For example, I fell a lot with the prosthesis. For example, when going downhill, the prosthesis was throwing out by itself. When you didn't control the knee, when you didn't contract or when you didn't contract yourself, the prosthesis was gone. For example, I had difficulties with it. There is a difference in terms of prosthesis. (new) Difficulty of prosthesisof course I could not use prosthesis (before amputation). I had a prosthesis made. At least with my old prosthesis, I had difficulty getting in and out of the car (as it was in one piece and didn't break in the knee). Now I don't have any difficulties after one gets used to it. I don't know whether to eat it or rub it on.. That's why you have to get used to it.....It became a necessity. What else could it be other than I need to adapt? You have to go, I'm like this. You will go to point c. You will continue. Or you will roll. You will walk. You will have to go, you cannot stay where you are. The wind has to blow, you have to keep sailing so that you can go. Let's use the wind..... of course, there won't be someone by my side all the time (Erdem, 24, university student)

Original: En başta ayağım var zannedip üstüne basasım geliyordu ama ayağımın olmadığını bilmediğimden artık benim için zorluk değil. Yeni protezime ayrıca dizüstü protez olduğu için eski protezle aynı değil. Onun dizini de kontrol etme ihtiyacım olduğundan dolayı zorluğu çektim 1 yıl. Protezle çok düştüm mesela. Yokuş aşağı giderken protez kendiliğinden atıyordu mesela. Dizi kontrol etmediğin zaman kasmadığın zaman ya da kendini kasmadığın zaman protez gidiyordu. Onda zorluk yaşadım mesela..... Protez açısından fark var. (yeni) Protezin zorluğutabi ki protez kullanamıyordum (amputasyon öncesi). Protez yaptırdım. En azından eski protezimle arabaya inerken binerken zorluk yaşıyordum (tek parça olup dizden kırılmadığı için). Şimdi hiç zorluk yaşamıyorum..... yani alışıyor insan. Atsan atılmıyor satsan satılmıyor. O yüzden alışman gerekiyor.....Mecburiyet oldu. Uyum sağlamam gerektiğinden başka ne olabilir? Gitmek zorundasın şöyle şöyleyim. Burdan c noktasına gitceksin. Ya süreceksin. Ya yuvarlancaksın. Yürüyeceksin. Mecbur gideceksin olduğun yerde kalamazsın ki. Rüzgarın esmesi lazım senin de yelken tutman lazım ki gidesin. Rüzgarı kullanasın..... tabi ki her zaman yanımda birileri olamayacak

From another point of view, Yağmur, who is likely to have her leg amputated again meanwhile interviewing, mentions the hardest part of getting used to have a prosthesis and lack of her leg. She wants to believe that she can get used to being amputated again, as she is used to this process.

I got used to walking with crutches, but I fell a lot (laughs). That was until the prosthesis was put on. After the prosthesis was inserted, I felt comfortable, it was very different to take a step again..... But now when I am myself, my sister also says, I have a sister. I think of you while I'm taking a bath. "I lift

one of my feet, I have a hard time stopping," she said. She said can you stand, I said I can stand. My husband made those irons to hold. I was getting support from the side. I'm used to. I can balance better on one leg. But of course, it is very difficult for bipeds. It's so hard to put themselves in the shoes of a one-legged person. I did it before it was cut. How can I climb stairs with one foot if my leg is amputated? I couldn't. But now I can do it all. I'm going up stairs, I'm going down stairs. I wasn't used to that either. But I'm used to that too. I adapted very quickly. My prosthetist said, there are some who wear it for 1 year and do not walk as well as you. But he said you adapted quickly, let me learn it right away, I want it right away. I don't like delays. I'm in a hurry that it should happen soon. I already put on the prosthesis early. They gave 8 months. I went to have it done right away in 5 months. Let me walk right now. I've been very busy with it. And I'm used to that too. I'll get used to it the way I got used to it. All the same thing. I was not used to any of them, I will get used to all of them, and I will get used to it. (Yağmur, 32, housewife)

Original: Değneklerle yürümeye alıştım ama çok düştüm (gülür). Protez takılana kadardı. Protez takıldıktan sonra rahat ettim tekrar adım atması çok farklıydı..... Ama şimdi kendimde de olunca kardeşim de söylüyor, kız kardeşim var. Banyo yaparken aklıma geliyorsun. Ayağımın tekini kaldırıyorum, durmakta zorlanıyorum dedi. Durabiliyor musun dedi bana, dedim durabiliyorum. Eşim o demirlerden falan yaptı. Kenardan falan destek alıyordum. Artık alıştım. Tek ayak üstünde daha iyi dengede durabiliyorum. Ama tabi iki ayaklılara göre çok zor. Tek ayaklı birinin yerine kendilerini o kadar zor koyuyorlar ki. Ben de kesilmeden önce yapmıştım. Bacağım kesilse tek ayakla nasıl merdiven çıkarım. Yapamamıştım. Ama şimdi hepsini yapabiliyorum. Merdiven çıkıyorum merdiven iniyorum..... buna da alışmamıştım. Ama hani buna da alıştım. Çok çabuk adapte oldum. Protezcim dedi 1 yıl takıp senin kadar iyi yürümeyenler de var. Ama sen çabuk adapte oldun dedi yapıp hemen öğreneyim, hemen olsun istiyorum. Gecikmeli asla sevmiyorum. Hemen olacak diye bir aceleciliğim var. Zaten protezi de erken taktım. 8 ay süre vermişlerdi. Ben 5 ayda hemen yaptırmaya gittim. Hemen olsun, hemen yürüyeyim. Çok uğraştım. E buna da alıştım. Buna nasıl alıştıysam ona da alışcam. Hepsi aynı şey. Hiçbirine alışık değildim, hepsine alışacağım, ona da alışacağım.

For a different point, Gürol believes that he was keeping on life by the mediatorship of his children and strengthening his relationship with God and the universe. Even he feels like he was supported by his wife and children, he sounded abandoned and rejected by his family in the first place while he was losing his health and struggling with poverty. In those times, he got strength from his spirituality. He pointed out that he reached a new level of perceiving the world even beyond the generations and concrete reality of world that he rejected his concrete reality, his body and absence of his leg at the same time.

I think it's because of the God. That's definitely the truth. When my little boy started to talk, after he was 2 years old, he was kissing my feet. He was kissing my healthy foot. It's a shame to say that when I entered the house with a crutch, I couldn't stop him, he hugged my foot and kissed my foot. This has been incredibly powerful to me. He speaks every evening with my amputated foot. It's called foot. Hello foot, how are you? Are you okay and he's trying to play with my foot. I think this is a power that God sent me through my child. Thank goodness ... These are the groups of 7-8 toys. They are fighting against evil. We brought this toy set from the internet. Here are all the little little figures, 7-8 cm that size (shows). He broke the right leg of all of them..... We were all the same age and at the same time in creation. At this point, as I said, he has come and gone in a child whose size is glazed, and he has spiritual knowledge. Here he is reading something from himself. And that gives me great strength. When I combine both the esoteric with the unknown and the apparent dimension, it gives me great strength... I was born in a family with a strong belief in Allah, I grew up like that... .. Are you saying that your whole creation is the universe or the world? That's the truth. If we are talking today. Amputated foot, I recovered after amputation. As I said, there is no sadness, both psychologically and spiritually, there is even happiness in it. If it were not for this, I would not have entered into this realization. I would not be able to perceive those truths. Normally some things can be realized. But there is nothing beautiful like living it and coming to its conclusion. (Gurol, 41, unemployed)

Original: Çok şükür yaratıcıdan kaynaklı olduğunu düşünüyorum. Kesinlikle öyle hakikat bu. Küçük oğlum konuşmaya başladığında yani 2 yaşından sonra benim ayağımı öpüyordu. Sağlam olan ayağımı öpüyordu. Eve değnekle girdiğim zaman ben onu engelleyemiyordum hemen ayağıma sarılıp ayağımı öpüyordu söylemesi ayıp. Bu bana inanılmaz ölçüde büyük güç oldu. Kesilen ayağımla birlikte her akşam konuşuyor. Ayak diye hitap ediyor. Ayak merhaba, nasılsın. İyi misin ve ayağımla oynamaya çalışıyor. Bu bana allahın çocuğum aracılığıyla bana gönderdiği bir güç diye düşünüyorum. Çok şükür ... İşte bunlar 7-8 kişilik grup. Kötülüklerle karşı savaşıyorlar. Biz bu oyuncak setini internette getirmiştik. İşte bütün hepsi küçük küçük figürler, 7-8 cm şu boyutta (gösterir). Hepsinin de sağ ayağını kırdı..... Hepimiz yaratılıştaki aynı anda ve aynı yaştaydık. Bu noktada dediğim gibi o surlanmış boyutu bir çocukta gelmiş gitmişlik var ve ruhen bir bilgi sahibi. İşte o kendinden bir şeyler okutuyor. Ve bu bana çok büyük güç oluyor. Hem batini bilinmeyen hem de zahiri görünen boyutta birleştirdiğim zaman bana çok büyük güç oluyor.... Allah inancı çok kuvvetli bir ailede dünyaya geldim, öyle büyüdüm..... onlar bütün oluşumun kainat mı diyorsunuz, evren mi diyorsunuz bütün oluşumun allahın özelliklerinin yansıması olarak görüyorum. Hakikati böyle. Biz bugün konuşuyorsak. Ampüte ayak, ampütasyon sonrası kendime geldim. Hem psikolojik olarak hem ruhsal olarak üzüntü olmuyor dediğim gibi bunun içinde hatta mutluluk bile var. Bu olmasaydı ben bu idrakın içine girmeyecektim. O hakikatları algılayamayacaktım. Normalde bazı bazı şeyler idrak edilebilir. Ama yaşanarak onun sonucuna varmak gibi güzel bir şey yok.

On the other hand, Sadık by accepting his new limits began to look for a proper job position for him to be able to have his own economic independence by putting his life on his teeth.

For example, a situation that delays my adjustment process is unemployment. Because you can't do what you want financially. You cannot go out as you wish. You cannot get what you want..... you cannot wear the prosthesis you want....., Turkish, history, mathematics, geography. I'm really trying so hard. I spent 2 months without a phone in my life. I completely turned off the phone. I disconnected from the external environment. I had a very short time and I had to complete it. I have completely left the illness, that psychology behind. Because I had no other choice. We have friends working in the private sector. Considering what difficulties, they had (Sadık, 30, public officer)

Original: mesela işsizlik uyum sürecimi geciktiren bir durum. Çünkü maddi olarak istediğinizi yapamıyorsunuz. İstedığınız gibi dışarı çıkamıyorsunuz. İstedğinizi alamıyorsunuz..... istediğiniz protezi takamıyorsunuz.....hocam Türkçe tarih matematik coğrafya. Yetiştirmek için çabalıyorum resmen. Hayatımda 2 ay telefonsuz geçirdim ben. Tamamen telefonu kapattım. Dış ortamla bağlantımı kestim. Çok kısa bir sürem vardı ve tamamlamam gerekiyordu. Hastalığı, o psikolojiyi tamamen geride bıraktım. Çünkü başka şansım yoktu. Özelde özel sektörde çalışan arkadaşlarımız var. Onların ne zorluklar yaşadığını göz önünde bulundurarak

Alike Sadık, Neriman also was getting prepared to the same exam which disabled individuals have a positive discrimination at the time interviews done which she might get benefit as Sadık did. She is on the way to take advantage of her new conditions, too to keep going on amputee life of her.

Another thing that Sadık benefitted from for both getting healthy exercised body also his passion football gathered is amputee football which he plays for the 3 years. He was pleased to keep football in his life for his psychological and physical health, additionally increased capacity to mobility and fitness approved by his doctors. Even if he has new limits in his life, he makes his plans by considering his new conditions by seeing the half full of the glass. Point of view to make new plans in life and accepting the limits might contribute to make the life colorful.

I love football. For example, even when I am amputated, the thing I felt sorry the most is that I can't play football anymore. I can say that I was more upset about it rather than losing my leg. I can say it's a passion for me since my childhood..... I've also been playing football for amputees for 3 years. Here are the comparative results of the previous year at the hospital I went to. How was it a year ago, how is it today. Here is the amputee, after I started playing football, I noticed that the results were better. The lungs developed more, became stronger, and the muscles became much stronger, all of which were

proven in the tests we conducted as evidence. So, for example, I feel more comfortable psychologically. I'm back to normal now. Sport is the most important point of my life. As long as I continue to do sports, I have such things in my mind that I will continue to stay healthy..... of course, the aspect of it is indisputable. When we throw out the problems we experience during the day, even during the training hour, and go on the field, the effects are definitely indisputable. So it helps me a lot in every way..... After I started the amputee football, I started to get less tired. Because of physical activity, the muscles began to get stronger. They observed more physical activity, more walking, more walking distance..... I'm thinking more about what I can do with my prosthesis in this situation. For example, I started swimming without prosthetics. (Sadık, 30, public officer)

Original: Futbolu çok seviyorum. Mesela ampütasyon olurken bile en çok üzüldüğüm nokta bundan sonra bir daha futbol oynayamama. Bacağımın gitmesine ampütasyon olmamdan çok ona üzüliyordum diyebilirim. Benim için bir tutku diyebilirim çocukluğumdan beri..... Hem bir de 3 yıldır ampüte futbol oynuyorum. İşte gittiğim hastanede bir önceki yılın karşılaştırmalı sonuçları oluyor. Bir yıl önce nasıldı, bugün nasıldı mesela. İşte ampüte futbol oynamaya başladıktan sonra sonuçların daha iyi geldiğini fark ettim. Akciğerlerin daha çok geliştiğini, kuvvetlendiğini, kasların çok daha güçlendiğini bunların hepsini kanıtsal yaptığımız testlerde tamamen çıktı. O yüzden mesela psikolojikman daha rahat hissediyorum yani. Artık normal bir seviyeye geldim. Spor benim hayatımın en önemli noktası. Ben spor yapmaya devam ettiğim sürece sağlıklı kalmaya da..... tabi kalmaya devam edicem diye böyle bir aklımda şeyler var zaten şey yönü de tartışılmaz. Gün içinde yaşadığımız sorunları antrenman saatinde bile atıp da sahaya çıkınca kesinlikle etkileri tartışılmaz. Yani her yönden bana çok faydası oluyor..... Ampüte futbola başladıktan sonra ben daha az yorulmaya başladım. Çünkü fiziksel aktivite, kaslar güçlenmeye başladı. Daha çok fiziksel aktivite, daha çok yürümeye, yürüyüş mesafemin daha çok artmasını gözlemlediler..... daha çok protezimle bu durumumla neler yapabilirim gibi düşüncelere giriyorum. Mesela yüzmeye başladım protezsiz.

Ongoing relationships also getting affected post amputation. This interaction can be both supportive and also overprotective but inhibitory for some of the amputees at the same time. However, even if it was overprotection, it is also way of caring anyway to appreciate the relationships. All the interviewees mentioned the value of support of their loved ones in many ways during all the amputation and post amputation process which can be interpreted as a good reason for them to keep and claim their lives.

Neriman was neglected during her sickness and treatment in the hospital by her husband and his extended family. However, her own parents and cousins took care of her in another city than their hometown and slept in the car for a few months before renting a place for another 7 months. This condition increased her gratitude to her own

origin family and relatives and even made it more valuable than it was for her to hold on life post amputation. She did not even want to talk more about the relationships disrupted in her life which can be heart like intense frustration, disappointment, and sadness in it.

In this process, my family and my side did not leave me alone.....they could have left too. They had been not looked after me. They could have said that she has a husband, let him take care of her. But when they saw that my husband was not interested, they took care of it more.....of course it felt good. So it was good in the next process. (Neriman, 33, housewife)

Original: *Bu süreçte benim ailem benim tarafım beni yalnız bırakmadı.....onlar da bırakabilirlerdi. Bakmayabilirlerdi. Eşi var eşi ilgilenin diyebilirlerdi. Ama eşimin ilgilenmediğini gördükçe daha fazla sahip çıktılar.....tabi ki de iyi geldi. Yani sonraki süreçte iyi geldi.*

Moreover, seeing not disabled and not accepting the disability can be a compliment for Neriman by her loved ones as it is heart by her being trusted to handle her own chores despite of her limits. She charges her moral batteries by their support, and she feels understanding for those both helping and not preferring to help her.

Nothing has changed in my social life. It still continues. I have friendships that go back many years. At first, I didn't want to go out, I didn't want to be in. But they did not leave me alone. I have friends who come to my door and say, "Let's go by car," it doesn't matter if it's a boy or a girl.... I got through that process easier with them. they never gave me the thought that you can't do it because I don't have hands. For example, I can pour a cup of tea. I can get something to eat. They didn't say you can't do it, sit down and let's do it. You can do it, you can do whatever you want, you can get it, you can do it. It's always been like this..... My adaptation process is as follows: After the amputation, the people around me supported me a lot in terms of mood and motivation. I mean, at the point where I said I gave up and I'm done, they said that I should not give up, it is a surprise every day that the sun will rise again every day... For instance, when I ask for a minibus to take me home sometimes, they were understanding. There were also the ones rejecting. You welcome everyone with understanding, so there's nothing you can do. (Neriman, 33, housewife)

Original: *Benim sosyal yaşamımda hiçbir şey değişiklik olmadı. Hala devam ediyor. Şöyle ki senelere dayanan dostluklarım var benim. İlk zamanlar çıkmak istemedim ortamlara, bulunmak istemedim. Ama onlar beni yalnız bırakmadılar. Kapıma kadar gelip, kapıdan arabayla hadi gidiyoruz diyen dostlarım var benim erkek kız fark etmez.... Onlarla o süreci daha kolay atlattım. yooook, onlar bana ellerim yok diye sen yapamazsın edemezsin düşüncesi hiç vermediler bana. Ben de kalkıp bir çayı koyabiliyorum mesela.*

Kalkıp bir şeyi yemeğimi çorbamı alabiliyorum. Sen yapamazsın, otur biz yapalım demediler. Sen yapabilirsin, istediğini yapabilirsin alabilirsin sen becerirsin. Hep böyle..... uyum sürecim şöyle: amputasyon sonrasında yanımdaki insanlar moral motivasyon olarak bana çok destek oldular. Yani vazgeçmemem konusunda ben vazgeçtim bittim dediğim noktada onlar vazgeçmemem gerektiğini her güne bir sürpriz her güne yeniden güneşin doğacağı..... Mesela minibüse rica edip eve çıktığımı biliyorum hani anlayışla karşılayıp tamam kızım dedi beni çıkartan insanlar da oldu. Ben çıkartmam kusura bakma kardeş deyip geri çeviren de oldu. Herkesi anlayışla karşılıyorsun yapacak bir şey yok yani.

Similarly, Sadık appreciates the support of his family better post amputation in terms of ongoing interest and thoughtfulness of his siblings, parents and friends.

After my amputation, I walk around the house with crutches. For example, because I was walking with crutches, my father changed all the tiled areas into parquet. He made such a change in the house.....They always supported.....I am really thinking right now.....as I said, amputation brought as much as it took. For example, I understood better the support of my family for me. Before that, my family tried to be as supportive as they could, but after that process, they were more interested and did not let me down. They took the claim on me..... Maybe if I had not experienced this disease and amputation, my bond with my family would not have been so high..... I always believed that my family was the biggest factor that relieved my pain and made me feel better. Their support, the support of the people around me, their prayers. I felt very big their support spiritually. They have been the biggest rehabilitation for me. For example, I have never received psychological treatment. I was asked to meet with a psychiatrist, I did not receive it. I was never left alone. By both my family and friends. They would come, we would chat, chat, or what do I know, when I was at home, they would call without asking, here we go, get ready. They would come in cars and pick me up. We would have gone outside. Here we used to walk around, they would try to distract me. They helped me get rid of that psychology as soon as possible. (Sadık, 30, public officer)

Original: Ben amputasyon olduktan sonra evin içersinde kanedyenlerle yürüyorum. Kanedyenlerle yürüdüğüm için mesela babam tuttu bütün fayans alanları parkeye çevirdi. Öyle bir değişim yaptı evin içersinde.....Ya hep destek oldular dediğim gibi amputasyon götürdüğü kadar getirdiği de oldu. Ailemin mesela bana olan desteğini daha iyi anladım. Ondan önce de ailem elinden geldiği kadar destek olmaya çalışıyordu ama o süreçten sonra daha çok hem ilgilenmeleri hem beni yarı yolda bırakmamaları. Sahip çıktılar....Belki bu hastalığı, amputasyonu yaşamasaydım ailemle bağım böyle yüksek olmazdı..... ben her zaman şuna çok inandım yani benim ağrılarımı dindiren benim daha iyi olmamı sağlayan en büyük etken ailemdi. Onların desteği, etrafımdaki insanların desteği, duaları. Ruhsal olarak çok büyük hissediyordum onları. Onlar benim için en büyük rehabilite oldu. Hiç mesela ben psikolojik tedavi almadım. Psikiyatristle görüşmem istendi, ben almadım. Hiç yalnız bırakılmadım. Hem ailem hem arkadaşlarım tarafından.

Gelirlerdi muhabbet ederdik, sohbet ederdik ya da ne biliyim evdeyken ben hiç aramadan sormadan ararlardı işte hazırlan dışarı çıkıcaz. Arabalarla gelirlerdi beni alırlardı. Dışarıya giderdik. İşte gezerdik dolaşırdık kafamı dağıtmaya çalışırlardı. O psikolojiden bir an önce kurtulmamı sağladılar.

Besides, he was also resented due to their overprotective and non-supportive attitude when he first initiated to begin to play amputee football. He feels like he lost his chance to be internationally representing the country.

I went to training for about 2 weeks, but during that period, my family put a lot of pressure on me... they did not want me go. I can even say they were trying to inhibit me.....What they were afraid of was that I only have one leg. If something happens to my leg, you'll be in a wheelchair. It will be more difficult for you to survive. It was purely because of their anxieties, fears..... that they were (feared) of me getting hurt. Since they put a lot of pressure, I was under their influence and unfortunately I quit during that period. (Sadık, 30, public officer)

Original: Ben de yaklaşık 2 hafta falan antrenmanlara gittim ama o dönem içinde ailem bana çok büyük baskı uyguladı... gitme diyorlardı. Hani engel olmaya çalışıyorlardı bile diyebilirimkorktukları şey tamamen tek bacağım olduğu için. Eğer o bacağıma da bir durum olursa hani tekerlekli sandalyede kalırsın. Hayatını idame ettirmen daha zor olur. Tamamen endişeleri korkuları ondan dolayıldı zarar görmemden (korktuklarından) dolayı. Çok baskı uyguladıkları için ben de onların etkisinde kalarak maalesef bıraktım o dönem içerisinde

He also mentioned about the constant support of his friends. Sadık, Neriman and Yağmur repeated the importance of their friend's stopping by them and *taking out by their friends*. For Yağmur, acceptance of their family and children contributed to their acceptance of new condition. Moreover, she was grateful to her husband and her children that they contribute to daily chores more than before amputation.

I said that it had to be cut because he was sick and hurt me. We said instead that the robotic leg will be attached. We said I'm going to be a half-robot, the way he would like it. He liked it because my mother will have a robot leg and my mother will have a robot leg. With that he consoled himself. Thank goodness we got over them that way. They accepted. I accepted too..... My husband is more helpful. Normally, I would say make breakfast once and wake me up (laughs).....He prepares breakfast, puts it, washes the dishes. He does it all. I said that's when I thought of it. I always wanted you to make breakfast, but I didn't want it like this (laughs) (Yağmur, 32, housewife)

Original: Hasta olduğu için bana zarar verdiği için kesilmesi gerekiyordu dedim. Robotik bacak takılacak yerine dedik. Yarı robot olacağım böyle onun seveceği tarzda söyledik. Hoşuna gitti annemin robot bacağı olacak annemin

robot bacağı olacak diye. Bununla teselli etti kendisini. O şekilde onları da atlattık çok şükür. Kabul ettiler. Ben de kabul ettim..... Eşim daha fazla yardım ediyor. Normalde derdim ki bir kere kahvaltı hazırla da beni uyandır (gülür).....Kahvaltıyı hazırlıyor, koyuyor, bulaşıkları yıkıyor. Hepsini o yapıyor. Dedim ki o an aklıma geldi. kahvaltı hazırlamanı istemiştim hep ama böyle olsun da istememişim (gülür)

However, acceptance of the families sometimes might turn to be overprotection and also feeling to be burden and not being supported for their own strength and inhibited. However, believing that she can do things make her feel more like confident about herself likewise her friends do contrarily to her mother.

My mother wouldn't make me do anything in case something would happen if I was hurt. That I will fall. I was opening the vacuum cleaner, it was running and taking it from my hand. He didn't have it because he couldn't resist, but it was very boring. It was like having a hyperactive child sit down. Thanks to my friends, they came and helped me, cooked my food, cleaned my house, and supported me, but people are afraid and embarrassed. They're close friends, but I already know what they're going to do.When they came, they were offering to do the cleaning, they were getting angry because you know who we have other than each other. You know, our friendship support is so good here..... They always seem to run to my problem, but they make me do all the things I can do. They said you can do it, no you can't, they didn't say get out. They have always been supportive. They said what can you do. They gave courage. I did not experience the lack (Yağmur, 32, housewife)

Original: annem hani canım yancak düşerim bir şey olur diye bir şey yaptırmıyordu. Düşerim diye. Elektrik süpürgesi açıyordum koşup elimden alıyordu Bulaşık yıkayım durduğum yerde yapayım bari diyordum. Kıyamadığından yaptırmıyordu ama o çok sıkıcı oluyordu. Hiperaktif bir çocuğu oturtturmak gibi bir şey oldu..... Sağ olsun arkadaşlarım gelip yardımcı oldular, yemeğimi yaptılar, evimi temizlediler, destek oldular ama insan çekiniyor utanıyor. Yakın arkadaşlarım ama yapacaklarını biliyorum zaten.Gelince işte temizlik yapalım diye teklif ediyorlardı, kızıyorlardı da hani birbirimizden başka kimimiz var diye. Hani arkadaşlık desteğimiz çok güzel burda..... Hep benim derdime koşuyor gibi oldular ama bütün yapabileceğim şeyleri yaptırıyorlar. Yaparsın ya dediler, yok sen yapamazsın çekil demediler. Hep destek oldular. Ne var ki yaparsın dediler. Cesaret verdiler. Eksikliğini yaşamadım.

Sometimes amount of gifts and get well soon wishes can be indicator of how much they got supported and loved in life to keep going on in life. Sabri sounded proud and pleasant about being even have to give away the presents for his convalescence period.

(All of my friends) have been very supportive. They told me that if I were the mayor, there would not be so many flowers as gifts. So we distributed the

flowers in the house and half of the gifts to the neighbor. (Sabri, 45, longroad driver)

Original: (Arkadaşlarımın hepsi) çok destek oldu. Bana dediler ki abi belediye başkanı olsa bu kadar çiçek hediye gelmezdi. Evdeki çiçekleri, hediyelerin yarısını konu komşuya dağıttık yani.

Even though Sabri was single before the accident and living with his sister, he had arranged marriage 7 months ago post amputation and he feels confident to *walk around with his wife to the grocery store by her side (Eşimin koluna girdim mi yürür giderim yani. Hiç bir şeye bakmam.)*. He began to a novel relationship rather than improving one; however, he sounded like he feels strengthened by his wife's arm and her support in the walkings that he thought he lost the endurance of it. Similarly, Sadık got engaged 1 months ago and he keeps going on life by building new relationships and bonds post amputation.

On the other hand, some of the participants mentioned that they had a new perspective in life which they put themselves in the center. Almost all amputees in this study mentioned that they had a new perspective in life not to be shy about stand by their own post amputation. After he got closer to the death, he stands in a more builder position in his relationships and also for himself.

I'm trying to look at things from a wider perspective right now. I learned not to act on the words of other person, but to listen to them..... There is a lot of difference. At first, I was the person who care the smallest things. I used to think about the smallest words of speech and think about them for days and break away from life. Because it is certain that all of us human beings will die one day. Life is short, sometimes I always say this, for example, I was afraid to say something. Even in my current relationship (romantic), it is very difficult for me to open up to someone before, but after experiencing all this, I think that life is too short, maybe I won't have time to say tomorrow. I can say that I have made a great progress in that direction. My self-confidence has increased. I express myself more easily now. (Sadık, 30, public officer)

Original: Şu anda olaylara daha geniş pencereden bakmaya çalışıyorum. O insanın sözlerinin laflarıyla hareket etmeyip, karşımdakini dinlemeyi öğrendim..... çok fark var ilk başta da en ufak şeyleri takan insandım. En ufak söylem sözleri aklıma takıp günlerce onları düşünüp hayattan kopan bir insandım ama bu hastalıkla ölüm arasındaki o süreci gördükten sonra ufak şeylerin takılmayacağını, aile içindeki durumların önemsiz kaldığını, gerçekten hayatın kısa olduğunu şu an çok algılıyorum. Çünkü hepimiz insan oğlunun bir gün öleceği kesin. Hayat kısa bazen her zaman şunu söylüyorum mesela bir şey söylemeye çekinirdim. Şu andaki ilişkimde (romantik) bile

önceden birisine açılmak benim için çok zor bir durumda ama bunları yaşadktan sonra hayat çok kısa belki yarın diyecek zamanım olmayacak diyorum. O yönden çok büyük bir gelişimim oldu diyebilitim. O özgüvenim o şeyim arttı. Şuanda kendimi daha rahat ifade ediyorum.

From another point of view, Gürol declares that he gained a novel view of himself as if like *he was reborn after almost like a labor pain (O ağrı sürecinde de ağrılı sancılı dönemde bebek dünyaya gelirken tabiri caizse sancılı bir dönem geçer ya benim bu idrak boyutumunu açan doğumuma sebep olan sancılı bir süreç vardı)* . He described himself as a more empathetic person post amputation. Different than Gürol, Erdem certifies his confidence and decisiveness post amputation in life and felt clarified about real meaningful things in life after the realization of the finality of his loss.

You know, I made a decision to do something, I did it. I can do whatever more I want right now. I am of that mindset. If I've decided to do something, if I'm doing it, it means I can do the things I put my mind to.....I mean, I'm thinking about what a person who gives up one foot should not go through...After suffering those pains (stump), I fell into my own trouble. What foot I do not care the foot! I thought so (laughs)..... Let's say you lost money somewhere. You lost your home. Your house burned. Your car burned. Instead of mourning them, it makes more sense to think about how I can make up for them. If your car is gone, it's gone. Is it more precious than your life? If my foot is gone, is it more valuable than my life? life goes on..... sometimes friends come and say I can't live without them etc. Are you calling this as a problem? No, I'm suffering from love, I'm going to kill myself like this. I do not know. The pain of love can be replaced by something better. You can love better, more beautiful one. Maybe there will be someone who loves you more than her life. This is something fixable. But our feet will never come back. Are you a lizard? Like his tail, your feet will not be replaced....It seems silly to us to fret over the things that can replace it. So no need to worry about others. It's not even worth worrying about, so to the others. Does it worth grieving? (Erdem, 24, university student)

Original: Hani bir karar verdim bir şey yapmaya, onu yaptım. Daha fazla ne istersem yapabilirim şu an. O düşüncedeyim bu açıdan. Bir şeye karar verdiysem yapıyorsam demek ki kafaya koyduğum şeyleri yapabiliyormuşum.....yani bir ayağından vazgeçen insan neyden geçmesin diye düşünüyorum.....o ağrıları (güçük) çektikten sonra kendi derdime düştüm. Ne ayağı bana ne ayaktan! Öyle düşündüm (güler)..... Diyelim ki bir yerde para kaybettin. Evini kaybettin. Evin yandı. Araban yandı. Bunlara yas tutmak yerine tam tersi nasıl telafi edebilirim nasıl yerine koyabilirim diye düşünmek daha mantıklı. Araban gittiye gitti. Canından kıymetli mi? benim ayağım gittiye gitti, canımdan kıymetli mi? hayat devam ediyor..... mesela bazen arkadaş geliyor, onsuz yaşayamam falan. Buna dert mi diyorsun içimden. Yok ben aşk acısı çekiyorum, kendimi öldürcem şöyle böyle. Ne biliyim. Aşk acısı, kaybettiğinin yerine daha iyisi gelebilir. Daha iyisini

sevebilirsin, daha güzelini. Seni belki canından çok seven biri olacak. Bu düzelebilir bir şey. Bizim gibi bir daha ayağa olmayacak yerine gelmeyecek. Kertenkele misin yerine gelmeyecek. Onun kuyruğu gibi senin ayağın yerine gelmeyecek..... Yerine gelebilecek şeylere üzölmek bize saçma geliyor. Diğerlerine üzölmeye gerek yok yani. Kafaya takmaya bile değmez yani diğerlerine. Yas tutuyor bir de ya, ne gerek var.

Erdem accepted the finality of his limb loss and he understood better worth of health not the other things can be compensated. On the other hand, Sabri and Gürol was already aware of their strength and resilience in their life and felt not affected by this hard life event in their lives.

Because I already know how resilient I am. So it wasn't hard for me either. (Sabri, 45, long road driver)

Original: Ben zaten ne kadar dirayetli olduğumun bilincinde olduğum için. Bu bana ayrıca zor gelmedi yani.

Neriman described her journey to be maturation and step up herself in her second chance in life. She understood the value of her life better post amputation.

I feel like I've matured so much. For example, I used to do more for people before, I used to compromise myself like that. I'm not giving now. So I'm not giving. I have been given a second chance to live in this world. (I thought) I was going to die... even the doctors were surprised that I was alive. Sure, and if I've been given this second chance, I'd rather live for myself. I want to live according to my own wishes. What they say, I don't hear any of it. Anyone can say and speak whatever they want. Before pointing at me with those fingers, I want them to show themselves and touch their own lives. (Neriman, 33, housewife)

Original: şöyle daha çok olgunlaştığımı hissediyorum. Önceden daha havaydım mesela önceden insanlar için daha çok şey yapardım böyle kendimden ödün verirdim. Şimdi vermiyorum. Yani vermiyorum. Ben bu dünyaya ikinci kez yaşama şansı verildi bana. Öleceğimi (sandım)... doktorlar bile şaşırıldılar yaşadığıma. Tabi ve bana bu ikinci şans verildiyse eğer kendim için yaşamayı yeğliyorum. Kendi isteklerim doğrultusunda yaşamak istiyorum. O ne dedi bu ne dedi, şu ne dedi hiçbirini duymuyorum. Her kim ne olursa olsun istediğini konuşabilir istediğini söyleyebilir. Öncesinde beni o parmaklarla göstermeden önce kendilerini gösterebilirler kendi hayatlarına dokunsunlar diyorum.

After being have to face with the death without dying, Neriman started to feel a strong desire to live for herself. Similarly, Yağmur gained a novel perspective in life which

she put herself in the center of her life comparing her pre amputation life as becoming a *selfish* person and not letting herself to be occupied with other's vulnerability.

Since you are going slowly, you notice everything while going. For example, you don't understand what's what when the car is going fast. I'm more aware of trees now (laughs). (Yağmur, 32, housewife)

Original: *Yavaş gittiğinden her şeyi fark ede fark ede gidiyorsun. Mesela araba hızlıca giderken neyin ne olduğunu anlamazsınız ya. Şimdi ağaçların falan daha çok farkındayım (gülür).*

Additionally, Gürol and Erdem mentioned that they had a new perspective in life which they appreciate the life, and nature, and even devaluing the importance of the other losses.

Gürol could not go out during his illness process for 3 years. After amputation was accomplished and he got healed, the world and life seemed quite different than before. After all these troubles in his life and body, being alive is still worth to feel grateful.

3 months after the amputation, I started going out with a battery car. And I saw that everywhere is heaven (laughs). I even saw how beautiful the leaf type of the most colorless, most disliked flower type was, the colors became clearer and clearer. The green space we are in now seems like a garden of paradise to me. At this point, a very positive process began. And socially, there is a cafe that I always go to. My wife's brother usually comes and goes there. It's nice, it's a good factor for me. Time passes there. Conversation love. Here I come to the park whenever I can. Time passes here. I breathe. (Gürol, 41, unemployed)

Original: *Ampütasyondan 3 ay sonra akülü arabayla dışarı çıkmaya başladım. Ve her yerin cennet olduğunu gördüm (gülür). En renksiz en beğenilmeyen çiçek türünün yaprak türünün bile ne kadar güzel olduğunu bile gördüm, renkler daha netleşti belirginleşti. Şu an içinde bulunduğumuz yeşil alan bana cennet bahçesi gibi geldi. Bu noktada çok olumlu bir süreç başladı. Ve sosyal olarak da hep gittiğim bir kafe var. Orda genelde eşimin abisi gelip gidiyor. Güzel oluyor bana iyi bir faktör oluyor. Orda zaman geçiyor. Sohbet muhabbet. İşte fırsat buldukça da parka geliyorum. Burda zaman geçiyor. Nefes alıyorum.*

To conclude, all participants mentioned about physical and psychological crutches to keep going on their life and the changes on their point of view in life. Firstly, they found ways to be mobile again such as; prosthesis and wheel chairs with battery by the aid of support of loved ones and also with the society. In addition to the improvement of current relationships, new ones were getting developed might be novel reasons to

hold on the life. As adaptation to changes provides a new look to themselves and the world, they mentioned the improved self-concept and world. After all hardships which some of them still challenges them, adaptation was so peculiar to each amputee.

3.2.4. Still There

All the participants declared that they still experience phantom pain even after years post amputation. The lived experience of phantom pain varies from one to another. Sometimes it is like a scratch and sometimes it sounds like a torture that their brain plays with them as if symbolizing the illness and the sufferings is still there or as if for “Oscar awards” with Yağmur’s words to have a feeling that the limb is still there. All the phantom pain experience was told to be getting less day by day might symbolize that the pain of limb loss also is a process that individuals getting used to. However, at the same time, no amputee in this study had the chance to get rid of them might symbolize that the pain of limb loss will never totally end, too.

Yağmur looked for psychological support for her phantom pain and accepting the absence of her leg was the way of treatment for her.

(after surgery) I felt really bad. Seeing that image.... OK, I knew where to cut it, but it was a strange sight. I was covered when I woke up. I'm trying to stretch my legs. Someone moved. I was trying to move the other one as if it was still in place..... I entered it prepared, but I couldn't even accept its appearance, I understood it. Then my pain started at work. But on the heel. At first I couldn't understand where I was hurting..... Later I understood. I said let me listen to my pain. My heel hurts, I was very surprised. I don't have a foot. My foot hurts very badly. My non-existent foot hurts. They said phantom pains.....I said how it hurts where there is no place. It seemed so absurd that..... There was pain, but it was not clear where it was..... It felt like there was a foot pain. I was constantly feeling that it was not there, but the brain did not perceive it. (Yağmur, 32, housewife)

Original: (ameliyattan) Çıktığımda kötü oldum. O görüntüyü görünce.... Tamam nereden kesileceğini biliyordum ama tuhaf bir görüntüydü. Üstüm örtülüydü uyandığımda. Hani ayağımı uzatmaya falan çalışıyorum. Biri kımıldadı. Öbürkünü kımıldatmaya çalışıyordum yerindeymiş gibiydi hala..... Ben ona hazırlıklı girdim ama görüntüsünü bile kabullenememişim onu anladım. Daha sonra işte ağrılarım başladı. Ama topukta. ilk başta anlam veremedim neremin ağrıdığını..... Daha sonradan anladım. Bir ağrımı dinleyim dedim. Topuğum ağrıyor, çok şaşırdım. Ayağım yok ayağım çok şiddetli ağrıyor Olmayan ayağım ağrıyormuş. Fantom ağrıları dediler.....Olmayan yer nasıl ağrıyor dedim. O kadar saçma gelmişti ki.....

Ağrı vardı ama nerede olduğu belli değildi..... Ayak var gibi ağrı yaptı. Olmadığını sürekli elimle hissediyordum ama beyin algılamıyordu.

Similarly, Gürol points out that acceptance of loss is the cure for phantom pain. Additionally, he believes in that if he can be away from alcoholic beverages, his phantom pain might be handled better. Therefore, it can be inferred that his way of interpreting his phantom limb pain and his way of coping depended on his religious belief system by staying away from a forbidden drink. For Neriman, it sounds like it is a reminder of her sickness period. On the contrary, it sounds like quite tolerable for Sabri.

it beats from time to time, not constantly. It hits every now and then..... something like before I was amputated like this, like the pain of necrosis. Knife cut, knife cuts away. It's like they're cutting my flesh alive like this (Neriman, 33, housewife)

Original: ara ara vuruyor geçiyor, sürekli değil. Ara ara vuruyor..... böyle ampüte edilmeden önce şey olmuştu ya, ne diyor kangren olmuştu ya kangren olduğu zamanki ağrılar gibi. Bıçak kesiği, bıçak kesip gidiyor. Böyle canlı canlı sanki etimi kesiyorlarmış gibi sanki.

Of course. It's like I have fingers. It's like it's itching. It happens every now and then. It's like my feet are itching. That's how the brain perceives it. You feel like you have no feet. The doctor said that these will continue for 5-6 years. The brain said, the reader said.....it's like 1.15-20 days a month right now. It used to happen. As he said, slowly the brain forgets. (Sabri, 45, longroad driver)

Original: tabi tabi. Parmaklarım varmış gibi. Arası kaşınıyormuş gibi. Ara ara öyle oluyor. Ayağımın altı kaşınıyor gibi. Beyin öyle algılıyor. Ayağın yok öyle hissediyorsun. Doktor dedi zaten bunlar 5-6 sene devam eder dedi. Beyin dedi okur dedi.....şu an ayda 1. 15-20 günde falan. Eskiden oluyordu da. Dediği gibi yavaş yavaş beyin unutuyor.

It should be noted that interpretation of phantom limb pain and phantom sensations are affected by the reason of loss and also this loss was perceived whether it is a painful separation of. For instance, it was a necrosis like pain for Neriman reminding her the way how she lost her limb, however, it was not very painful for Sabri as he lost his limb in an instant traffic accident and his interpretation to his loss was also as if quite slightly painful for him. Similarly, Erdem's experience is getting less disturbing for his life day by day. His interpretation to amputation was not terrifying compared to Yağmur and Neriman likewise his interpretation to his phantom sensations which *does*

not affect his life. On the other hand, after 9 years, the effect of phantom pain is still unbearable for Sadık especially after the phantom limb pain fade away:

3 times in a year max.... 1-2 times a year, maybe it doesn't last 2 minutes. But after that, I can say that the effect it leaves is 1 hour (laughs)..... it is so bad that it happens with unbearable intensity, as if 40 needles were getting pressed at the same time. After that, the pain begins to subside gradually. The body is starting to recover. But it seems to me that I still feel the psychological effects of pain on my body. Will it happen again in the same way or not? (Sadık, 30, public officer)

Yılda 1-2 defa maksimum 3.....Toplasan belki 2 dakika sürmüyor. Ama ondan sonraki bıraktığı etki 1 saat diyebilirim (güler).....çok kötü hani dayanılmaz şiddette gerçekleşiyor sanki aynı anda 40 tane iğneyi bir anda basarlar gibi. Ondan sonra birden ağrı kesilmeye başlıyor yavaş yavaş. Vücut toparlanmaya başlıyor. Ama ağrının psikolojikman bıraktığı etkiyi halen vücudumda hissediyormuşum gibi geliyor bana. Yine aynı hemen aynı şekilde bir daha olacak mı olmayacak mı?

Different than the others, Sadık got amputated almost 9 years ago whose phantom limb pain still reminded the bad memories of his cancer that the reminder of absence of his limb might be connected in his mind with the cancer is *still there*. Even though he accepted his limb loss and adapted his amputated life quite well, his phantom limb pain reminded his death threat.

All in all, phantom pain of each amputee gave a subjective meaning in accordance with their internal meaning to the amputation. For instance, it reminded their former pain for Sadık and Neriman when the time they were suffering from their illness. Additionally, Yağmur interpreted its lack as if she cannot accept her limb loss. On the contrary, Sabri declared that he did not give lots of meaning to them like he did not give lots of meanings to his amputation.

CHAPTER 4

DISCUSSION

4.1 Overview of the Findings

Limb loss is a life-changing circumstance bringing physical, psychological, social and environmental change at a time (Peirano, & Franz, 2012). This dissertation provides both a general basic evidences to the existence of PG in amputees and also a unique, in-dept, idiographic point of view to the grief especially to the prolonged grief and adaptation process of amputees after amputation even if it was not aimed to be investigated. In fact, I wanted to examine the prolonged grief experiences of amputees, it won't be wrong to say that multiple losses in addition to the limb loss simultaneously, such as; loss of job, spouse, and non-disabled identity, independence and body wholeness following amputation are intertwined and hard to discriminate the psychological burden of them one to another. Each loss separately contributes in varied ways uniquely to the grief experience and psychological distress of amputees. Moreover, each individual has their own unique ways of coping and adaptability capacity to keep going on their lives and process their grief and the traumatic experience they had. Not only adversity, but there can also be a growth with this sharp incident. Therefore; lived experience of limb loss is quite heterogenous and peculiar to the individuals' capacity to grief and personal history. Whilst the cause of amputation depends on the similar factor, the responses and the psychological prognose of the amputees became varied. In despite of these diversity, there were also common ways of thinking and feelings and lived experiences independent from the cause of amputation and the appendages being amputated, and even also the years spent post amputation among respondents. To put in another word; even though it is a forced choice due to health problems to survive or a sudden loss due to a traffic accident, amputation brings plenty of changes in the ordinary flow of life to be adapted

such as giving a break or giving up to the current job or to learn walking with prosthesis like a new-born baby. Furthermore, facing with the lack is inevitable independent from the number of limbs amputated and location of it. In addition to those, phantom pain might be a reminder of the amputation itself despite the years spent.

4.2. Evidence of Prolonged Grief in Amputees

Findings of Study 1 demonstrated that individuals losing limb might suffer from prolonged grief. PG-13 had one factor structure likewise in the adaptation of Turkish PG-13. Results of Explanatory Factor Analysis (EFA) was appropriate additionally, internal reliability of PG-13 on amputee sample was found to be appropriate (Büyüköztürk, 2002). Moreover, the findings were congruent with the adaptation of PG-13 into Turkish and original scale (Işıklı et al., 2020).

25.2% of participants in Study 1 fit the criteria of PG-13. Pomeroy, Coudane, Dap, and Dautel (2020) reported 38% of traumatic upper-limb amputee had complicated grief according the findings of their retrospective design study in France. The difference between the percentages might be explained with the study design and measurement tool chosen, and sampling methods. While they used retrospective study design, Inventory of Complicated Grief (ICG, Prigerson, et al, 1995) as a measurement and systematic sampling; cross-sectional design, PG-13 and convenience and snowball sampling was used in Study 1. Different than their specific hand loss in sample, I focused on the loss of limb and its number rather than the area and the level of the loss in Study 1 as the number of losses might contribute to the prolonged grief. On the other hand, the participants filling and reaching to both paper-pencil and online study might be the ones already more functional and adapted to their novel situation to look for prosthesis in orthosis and prosthesis centers and to participate in internet base research. This is why the proportion of amputees experiencing prolonged grief might not represent the population which might be interpreted as a pioneer study focusing on the role of prolonged grief to shed light in psychological distress and rehabilitation process of amputees.

On the other hand, According to National Survey of America, %95 of amputees declared that they at least 1 amputation-related pain in duration of 4 weeks which

almost %80 of amputees had phantom pain described as disturbing and severely painful (Ephraim, et al., 2005; Hogan, et al., 2022). Similar findings pointed in previous studies that 49- 88% of amputees are affected by phantom limb pain (Culp, & Abdi, 2022; Ehde, et al., 2001). In Study 1, perceived residual and phantom limb pain in terms of frequency and severity was found significantly associated with PG as the sensations might act like a mnemonic of their loss. Hence; existence of perceived residual and phantom limb pain might be contributors of PG in amputees. Similarly, Pomeroy, and colleagues (2020) reported that amputees with prolonged grief had higher percentages of nociceptive, neurological, and phantom limb pain complaints compared to amputees without prolonged grief. In the same way, all participants of IPA had phantom sensations. As amputation is a limb loss mostly bringing phantom sensation and pain and residual pain with it, phantom sensations and residual pain are becoming a part of the absence experience. Actually, the superordinate theme called “still there” was a common interpretation of respondents that interestingly sense of presence was also a cognitive structure in experience of yearning of mourners (Worden, 2018). For instance, Yağmur is the one fitting PG-13 criteria and had still having hard time to accept the new limits of her amputated body and missing her leg a lot and furious about her loss. Additionally, she was about to face with being amputated again at the time interview was conducted. Her experience to this separation was horrifying for her and even looking at the absence was hard for her. However, for Neriman and Sadık, phantom pain was a torture reminding of their former illness which had a realistic death threat. On the other hand, Gürol found meaning for his experience regarding his lifestyle and religious belief system which he tried to exclude alcohol and caffeine from his life which is forbidden by God and marketed in capitalist life to be more awake. However, the phantom sensation was more bearable for Sabri and Erdem without PG. All in all, there can be a relation between phantom pain and grief, and PG as regard to interpretation of phantom sensation by amputees in accordance with grief capacity and personal history. Persistence of phantom pain can be resembled Horowitz’s avoiders who bereaving little at the time loss followingly imitating the symptoms of person who died as regard to avoidance or repression of grief after the loss (Maguire, & Parkes, 1998). Moreover, as long as time pass post amputation increased the possibility of PG and perceived residual and phantom limb in terms of frequency decreased was another important finding of the Study 1.

Therefore; time pass after amputation might be interpreted as a determinant for both residual and phantom limb pain's disturbance and possibility of PG.

In addition to those, perceived nature of loss was rather than the reason of loss might be regarded as an important factor determining prolonged grief despite the fact that perceived nature of loss was not found to be associated with PG. All amputees with PG expect one (96.2%) reported that they were not expecting their loss in Study 1. The results can be supported by "*the life becomes upside down*" theme of IPA findings especially with Yağmur's words that "I never thought of being a person with disability" (*Benim de engelli olacağım hiç aklıma gelmezdi.*). even if there was a medical reason to be amputated, individuals with medical condition might believe in getting better without loss and deny the possibility of being amputated in the second worst case scenario after dying which might result in being unprepared the idea of losing their body part. Besides, having paralysis can be perceived as more sadness-provoking idea than dying (Koca-Atabey, & Öner-Özkan, 2014). Amputees were the ones that making the forced choice of having disability to be able to survive.

In grief literature, nature of loss whether is unexpected was an important factor to predict prolonged grief. However, it might be different in amputee sample. Even the participants especially for those having health problems, they hope to get heal without losing their limb during treatment process even if they are informed about the possibility of amputation. Persistence of body integrity is expected by default in human beings; as individuals do not count the possibility of losing some body parts and losing it. All respondents, except Sabri, made a forced choice for their amputation decision to be able to get rid of from their illness and extreme sufferings or to avoid possible illnesses. Due to absence of research linking losing body parts and prolonged grief is arguably surprising, prolonged grief of assisted death researches were considered which might shed light on the findings of IPA. According to the qualitative study of Gamondi, and colleagues (2013), families being actively involved in assisted suicide decision of their loved ones declared less emotional distress and playing a role in informing authorities and conducting to rituals to be able to say good-bye (Beuthin, et al., 2022). Besides, family members preferring passive role in decision making process had the burden of moral dilemma which was interpreted as a risk factor for PG. Furthermore, Fish (2017) proposed the family members of physician assisted suicide

individuals getting informed about the procedure were more likely the ones being away from the risks of PG. Considering these novel researches in terms of bereavement literature, being involved in the decision-making process of having amputation and getting informed about the possible consequences of not being amputated might be protective factors from PG for amputees unless it was not a sudden loss likewise in Sabri's case due to accidents. On the other hand, Gershfeld-Litvin (2021) revealed that as mastectomy was a life-saving procedure for women with breast cancer, ambivalence of surviving might hinder to grief of their loss of breast. Moreover, having a fixed date for assisted death provided time for farewell for some of family members as a positive experience for sense-making (Beuthin, et al., 2022) which can also be protective from PG. Similarly, having a fixed date for surgery for amputation might provide time for amputees to say goodbye to their limb. Consequently, perceived nature of loss can be a risk factor for amputees' PG and giving the decision of being amputated might be a protective factor for the prognosis of grief process.

All in all, individuals with limb loss might experience PG and, perceived existence of residual and phantom limb sensation, time pass post amputation, perceived nature of loss, giving the decision of being amputated might be the determinants or factors affecting the possibility of prolonged grief.

4.3. Experience of Limb Loss

4.3.1. Meaning of Amputation

When limb loss emerges in the case of health problems; such as, cancer, vascular diseases; explosions, accidents; amputees most probably face with the possibility of dying. Therefore, amputation was regarded as a medium choice in between life and death by letting the death of some parts to be able to let the rest of the body survive. Having amputation brings intense, ambivalent feelings of both surviving and getting closer to death. According to Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), "A" criteria of Post-Traumatic Stress Disorder (PTSD) diagnosis is "*directly experiencing*" "*actual or threatened death or serious injury or sexual violence*" (APA, p.271). Trauma can also be defined as intense physical and psychological reactions to the experiences (Center for Substance Abuse Treatment,

2014). In accordance with trauma literature, possibility of dying and losing the body integrity can be experienced as traumatic. This is why each amputation can also be regarded as traumatic due to loss of body wholeness and facing with the possibility of death in most cases. Trauma should be considered as a possible diagnosis for amputees. However, Phelps, Williams, Raichle, Turner, & Ehde (2008) criticized that although there are many studies in the literature on traumatic injuries and life-threatening situations, number of studies was limited in literature focusing on PTSD of amputee population despite its traumatic nature. Additionally, traumatic side of limb loss and the grief coming with loss experience cannot be considered separately. Research demonstrated that PG was a distinct concept than PTSD in terms of being overly occupied with the loss even though there is an overlap between symptoms interacting bidirectionally (Djelantik, et al., 2020; Wen, et al., 2022). Giving meaning to the experiences was an important part of digestion of traumas and losses and prolonged grief (Worden, 2018). Grief and trauma might interact bidirectionally mostly in violent which was called as “traumatic bereavement” according to Stroebe, Schut and Finkenauer (2001 as cited in Worden, 2018, p. 19). However, understanding traumatic nature of losing limb was out of the scope of this dissertation, it might be enmeshed with grief processes of respondents. Even though the semi-structured questions were lack of understanding the traumatic side of the amputation lived experience; trauma and posttraumatic growth had become a subject in the adaptation and adjustment to limb loss (see *adjustment and growth*).

Furthermore, all amputees of this study used religious coping and declared that amputation was their faith except Yağmur and Erdem is the only one rejecting the idea that amputation was the test of his life. Firstly, amputation is an experience splitting sharply the life into two periods as before and after. Therefore, it deserves and requires an important meaning for the ones being have to be exposed to this condition. Respondents of this dissertation gave meaning to their amputation as *the test in life* given by God to examine their gratitude or rebelliousness.

99% of the Turkey population is Muslim according to 2021 Report on International Religious Freedom (2022) which affects the individual’s way of thinking and perception about what they are getting through in life. According to Quran (7:155), human being is tested whether to deviate or to lead to the right path due to challenging

life events such as earthquake by God in world. In Islam, both sickness and healing are coming from Allah but from no other entity (Akçakaya, & Can, 2022, p.206). According to study of Yılmaz-Karabulutlu, Yaralı, and Karaman (2019) conducted in Turkey, level of faith and spirituality increased in Muslim patients diagnosed with cancer. In difficult situations, such as illnesses, patients use their religious beliefs by praying and worshipping as they were looking for shelter and omnipotent power to be able to cope with feelings of desperateness and adjustment to their loss (Akçakaya, & Can, 2022, p209). However, increase in religious activities in crisis time is not peculiar to Islamic belief. Literature provides evidence that life-threatening diseases and crisis mostly turned individuals to the religion and spirituality (McClain, et al., 2006). In addition to benefit of handling challenging situations, the strategies of spiritual coping facilitated personal and spiritual growth and increased quality of life (Peirano, & Franz, 2012; Pentaris, Patlamazoglou, & Schaub, 2022). Religious coping can be defined into two ways as positive and negative. Positive religious coping includes giving spiritual meaning to pain and suffering and asking for help from God to be able to solve problems. Positive coping was found to be related decrease in psychological and physical symptoms, enhancing life quality and psychosocial adjustment. However, negative religious coping involves feeling sinful or punished or forgotten by God resulting decrease in quality of life, and life satisfaction and increase in psychological distress and symptoms and desire of death (Holt, et al., 2011; Tarakeshwar, et al., 2006).

Additionally, increasing number of research supports significant role of faith and religious strategies used in grief for the purpose of maintaining valuable connections with the deceased, accepting the finality of the loss, accessing social support, and making meaning through bereavement (Pentaris, Patlamazoglou, & Schaub, 2022). Grief initiates more use of religious strategies (Kokou-Kpolou, et al., 2018). Suicide, homicide and fatal accidents are the losses that more difficult to digest (Currier, et al., 2011). Religious coping and support, spirituality is used to give meaning to the loss and PG as a protective factor for mourners (Biancalani, et al., 2022; Kokou-Kpolou, et al., 2018) which were mostly unexpected and violent deaths, such as, homicide (Burke, et al., 2011; Neimeyer, & Burke, 2011), stillbirth (Popoola, Skinner, & Woods, 2022) and challenging crisis like losses during Covid-19 pandemic (Biancalani, et al.,

2022). The findings were congruent in across different cultures and religions. At that point, amputation can be regarded as an unexpected loss for people having body integrity. The research conducted on Nigerian mothers in bereavement revealed that the experience of stillbirth was affected by religious and superstitious and religious social expectations. These beliefs played significant roles in how mothers coped with the loss, by providing them with a framework for sense-making and benefit-finding (Popoola, Skinner, & Woods, 2022). Neimeyer and Burke (2011) found that negative religious coping was a significant predictor of complicated grief in the sample of African American homicidally bereaved adults. On the other hand, positive religious coping facilitated to the adjustment to bereavement (Burke, Neimeyer, McDevitt-Murphy, Ippolito, & Roberts, 2011). Moreover, engaging in spiritual and religious activities was found to a way of coping to grieve for their sibling's death (Lövgren, Sveen, Steineck, Wallin, Eilertsen, & Kreicbergs, 2019).

Moreover, research demonstrates that amputees use spirituality and religious cope with limb loss (Peirano, & Franz, 2012). For instance; Buddhist religious activities were found to be useful for decreasing levels of depressive and PTSD symptoms in veterans (Zoysa, & Wickrama, 2011). In this IPA, five of the participants used giving religious meaning to their limb loss and positive religious coping by using prayers and asking patience and forgiveness from God. On the other hand, Erdem projected his anger to God due to his unfair test and rejected the idea of being tested unfairly as being a person with disability inborn by using negative religious coping. Although he reached a point that he desired to take responsibility of his life which might be a growth for him as an adult despite the fact that he cannot benefit from the positive religious coping. Additionally, 6 participants attending Study 1 refused the answer the 6. item of BDI which is about sense of being punished and took note that this was an *irrelevant or inappropriate* question to their condition. It can be inferred that these participants were sensitive to the idea of being punished in life and rejected the idea that amputation is a punishment to them. Sawyer, and Brewster (2019) claimed that atheists had less psychological distress after traumatic events when compared to believers as they were less likely feeling anger and praying without expecting to get better. Even if there is no concrete information about the participant's religious beliefs in this dissertation, unable to express anger to God to be able to

grateful and not rebellious no matter what happens, and suppression of these undesired emotions may also block the normal grieving and might be a risk factor for PG. Praying might be both for contacting God to find power and patience for the current painful situation and also unable to change the irreversibility of their loss at the same time. This ambivalence might cause the weakening of attachment to God. This is why positive and negative religious might be transient between them rather than a stable state when the hardship of changes and duration of adjustment were taken into consideration. Furthermore; Kokou-Kpolou, and colleagues (2018) proposed that especially negative religious coping deserved a special attention in order to be protected from the risk of PG especially if the loss was sudden, unexpected and traumatic.

To conclude, especially after violent and unexpected losses like homicide and amputation, mourners tend to interpret this life event is a test given by God or it is their faith. While positive religious coping might be beneficial to give meaning and to grive, negative religious coping might turn to be psychological burden for amputees in terms of seeing themselves unliked or punished by God which might complicate the grief processes and be a risk factor for PG. On the other hand, suppression of undesired feelings directed to God or universe whether causes the PG is not well-documented but might be a risk factor.

4.3.2. Facing with the Absence of Limb

Additional losses and changes which also increases the possibility of prolonged grief by bringing enmeshed grief processes. Life being upside down was a common feature for amputees might influence psychosocial adjustment. Initially, amputation was a loss of capabilities for all which brought sense of incompetence and missing the limb and former life and lived experiences. Consequently, especially amputees having a job might need to change their occupation caused a vocational, additively loss of economic dependence and exposure to money scarcity which endanger the functionality, adjustment, and psychosocial well-being of amputees.

Schoppen, and colleagues (2001) revealed that 78% of lower limb amputees stopped working within 2 years postamputation due to amputation-related reasons in Dutch population. Besides, while 22-67% percent of lower limb amputees kept going on their

same job, the rest of them had to change their job. In another study conducted in America, it was found that 29% of upper limb amputees changed their job, and almost 61% of them were currently working even though it was still under the average of national population (Lee, et al., 2022). Returning to job rate was found to be almost 66% according to many studies (*See review Burger, & Marinček, 2007*), 89% according to Millstein, Bain, & Hunter (1985) and 79% according to Schoppen, and colleagues (2001). Contradictory results might be related to the small sample sizes and amputees willing to participate in research might be the ones more functional and having high levels of well-being. Level of education, necessity of less physically demanding jobs, level of phantom limb, and stump, and multiple amputations, age of amputation, use of prosthesis, to be able walk distant are the factors affected the return to occupational life (*Burger, & Marinček, 2007; Lee, et al., 2022; Millstein, Bain, & Hunter, 1985; Schoppen, et al., 2001*). On the other hand, educational, annual household income and disability, level of pain benefit was found be related to employment status while level of amputation, prosthesis use was not related to return to working in veteran sample (Hawley, et al., 2022). In this study, Sadık had to change his job and return to working, Erdem was already working as an individual with disability, Gürol stopped working, and Sabri kept his same job, Yağmur was not planning to working and Neriman was planning to work even before she was not. Studies demonstrates that, men are more likely develop concerns about functionality (REF), while women mostly have concerns about their body image (Ward Khan, O’Keeffe, Nolan, Stow, & Davenport,2019). In this distertation, men mentioned their vocational and financial concerns while Yağmur was mentioning about her body image concerns. Gow, MacLachlan, and Aird (2004) declared that boundaries of self was becoming ambiguous with prosthesis use in terms of functional and emotional identification. Furthermore, amputation brought aesthetic concerns for some and identity with disability in many cases which requires adjustment to their novel self and identity. Social and identity disruption after a loss is one of the PG criteria (Prigerson et al., 2009)

However, being rejected to loved ones post amputation might not be helpful as regard to adaptation to this identity. This is also can be seen and loss of loved ones and loss of status. Neriman was also grieving for the loss of her marriage and husband as they

decided to divorce post amputation. Her grief might be severe as she was supposing that their relationship was quite good before amputation as severity and intensity of grief after lost spouse is determined with the perceived quality of their relationship (Kokou-Kpolou, et al., 2018). Moreover, all of a sudden, being exposed to the stares and pity of society was quite fresh for amputees, coping with stigmatization was another hardship needed to adjustment. Disability can be seen as a minority group in an ableist society (Ünal, 2018) attracting attention to discrimination and stigmatization (Buljevac, Majdak, & Leutar, 2012). Pitying the people with disability and overprotection were also classified as prejudiced social support (Buljevac, Majdak, & Leutar, 2012) which disturbed Erdem excessively. On the other hand, Saradjan, Thompson and Datta (2008) revealed evidence that amputees experience a process of desensitization to the stares in years like Sadık reached that point.

From grief literature perspective, multi losses were regarded as a risk factor for prolonged grief (Worden, 2018) as each loss brings its own inevitable grief (Volkan and Zyntl, 2010) overlapping in amputee's lives in terms of the occupation, romantic and family relationships and perceived loss of status in the eyes of society by gaining the identity with disability and loss of trust to authority figures. Additionally, there were grief reactions in the quotes that missing the limb itself, its functionality, feeling anger to its absence, rejection of body itself to avoid the absence of limb and almost denial of loss which can be evaluated in accordance with the duration of feelings and disruption in functionality. Especially, Yağmur and Gürol, Neriman having PG-13 scale are at the risk of diagnosis.

4.3.3. Adjustment and Growth

Amputation influences amputee's independence, mobility, well-being and quality of life (Murray, & Forshaw, 2013; Torbjörnsson, et al., 2022). However, according to Volkan and Zyntl (2010) each loss can be a tool to growth and renovation if the grief can be completed. In clinical practice, loss can be conceptualized broadly beyond bereavement and addressed with the potential for posttraumatic growth (Klurfeld, Buqo, Sanderson, & Ward-Ciesielski, 2020). Followingly, posttraumatic growth literature was benefitted to explain the growth of amputee respondents.

First of all, using prosthesis was a compensation to losing limb and its functions. Positive adjustment to amputation and prosthesis use is an important part of rehabilitation in terms of re-gaining mobility, independence and self-efficacy. Sinha, van den Heuvel, & Arokiasamy (2014) demonstrated that vocational status, using prosthesis and assistive device daily were the most important factors to adjust amputation and prosthesis. In addition, they reported that medium satisfaction with the functioning of prosthesis was associated with moderate psychosocial adjustment and not being restricted in functional and social activities just except for athletic activities. Torbjörnsson, and colleagues (2022) found that amputees using prosthesis compared to using wheel-chair had greater increase in quality life; however, non-prosthesis user did not show any significant change in quality of life after one-year follow-up.

Secondly, amputees mentioned in the positive realizations in their lives postamputation. These are better appreciation of current relationships and getting new bonds, getting new hobby and occupation, spiritual enlightenment, enlarged point of view about life and human relations, discovering other sides of their self and maturation. According to Tedeschi, and Calhoun (1996, 2004) individuals might reach a better personal improvement following a traumatic experience into 3 areas which are perceived changes in self, a changed sense of relations with others, and a changed philosophy of life. Then, these broad areas were divided into five categories as relation with others, new possibilities, personal strength, appreciation of life and spirituality. Similarly, spouses of male veterans declared that they witnessed in changes of their husband's lives in terms of strengthened family ties and connections; greater appreciation for and perspective on life; new career and educational opportunities; stronger, more resilient as a person; and formed new relationships, friends, and connections postamputation (Bartone, & Bowles, 2021).

Besides, personality characteristics also contributes the adjustment and growth of amputees. Hardiness is of the most important factor predicting posttraumatic growth and well-being of male veteran amputees (Bartone, & Bowles, 2021). Hardiness can be described as positive reframing of negative experiences as opportunities and challenges to overcome, and taking action to solve problems. Moreover, Miller, and colleagues (2020) revealed that amputees having effective use of coping skills,

cognitive flexibility, optimism, skills in facing fears, and social support to attain meaningful goals and also had higher levels of resilience.

In the rehabilitation process, Rage and Rowe (1998) indicated that patients having physical and psychological problems are the ones who are source of support to encourage each other to get better and talk about their phantom pain and even giving advice about the situations that they can't handle easily. Amputee football is one of the areas that mostly men gathering around a ball to play together and just playing football rather than facing with real life problems.

Anderson, Roubinov, Turner, Williams, Norvell and Czerniecki (2017) demonstrated that perceived social support is a moderator in the relationship between daily activities and level of depression among unilateral lower limb veteran amputees. Therefore; increased level of perceived social support predicted increase in daily activities. Moreover, quality of life was significantly affected by perceived social support (Jumalewy, et al., 2022). Research conducted in Sri Lanka demonstrated that support of family and friends decreased perceived depressive symptoms and PTSD symptoms of veterans (Zoysa, & Wickrama, 2011).

Even if it is a peculiar experience to each individual in terms of how the specific conditions occurred for amputation, psychological prognose after amputation; the risk for prolonged grief should be taken into consideration due to the unexpectancy of limb loss and additional losses to the limb loss.

4.5. Importance of the Dissertation

Prolonged grief after a limb or an organ loss is surprisingly not well-documented (Pomeras, et al., 2020). Therefore, this dissertation was aimed to fill the gap in the literature by providing evidences to the trace of PG in amputees. The study might be regarded as a pioneer focusing on prolonged grief on amputees

First of all, amputees suffer from prolonged grief more than individuals losing their loved ones which grief counseling might have an important role in the rehabilitation programs. In addition, this dissertation provides evidences to the relationship between residual and phantom limb pain and PG. Especially phantom limb pain and sensations

experienced and perceived as disturbing phenomena by individuals with limb loss has still its own dark sides and lack of treatment. Even though it cannot be inferred that PG shed light into this experience, findings of IPA demonstrated that phantom sensations might be interpreted in accordance with the sense-making with the limb loss. For instance, Erdem and Sabri were the ones without PG interpreted their phantom pain as less disturbing than the other respondents. Hence, grief counseling and sense-making to their loss might be beneficial for the sake of decrease in phantom pain.

Furthermore, IPA provided a pioneer framework for prolonged grief literature. In addition to those, findings showed that amputation can be a bridge between death and life with a cost of grieving with loss of limb and the life before amputation and necessity to the adjust the changes coming with limb loss. Moreover, it supported robust evidences to the role of religious coping and sense-making in amputation. Additionally, mood fluctuations with the changes in physical well-being, alteration in the view of self, the others and the society and the world, re-gaining independence and mobility, experience of phantom limb pain were also reported with their voices. On the other hand, the findings provide preliminary evidences to the lived disability experience in Turkey. Individuals with disability were exposed to discrimination and stigma but at the same time support of their loved ones which can be a reason to hold on life.

4.6. Limitations and Suggestions for Future Studies

The current dissertation has several limitations. First of all, amputation is a sensitive topic not only for those both experiencing to talk about and also challenging for witnessing as a family member and even as an interviewer. At this point, appropriateness of the research methods chosen for this study can be debated. As data collection from amputation was a challenging process and the sample size was quite under the number of sample size was planned due to invalid and incomplete data. This is why the results can be interpreted as only preliminary. On the other hand, data collected from prosthesis center and by via online announces might be biased in terms of reaching the only amputees planning to use prosthesis and also using internet effectively most likely being more functional than the others with psychological

breakdown. Therefore; representatives of the sample can be another debatable issue of this study. The findings cannot be generalized for the amputees clinically suffering from prolonged grief. Amputees were having complaints about number of questions might have problems about re-evaluating their psychological conditions by remembering the psychological burden on their own due to self-report. Moreover, cross-sectional study design has its own limits hindering the cause-effect relationship and prognose of the prolonged grief in different phases. Longitudinal studies might shed light on within changes that participants getting through rather than between participants in amputee sample.

Besides, IPA, might be a debatable methodology for the lived experience of amputation whether the participants are able to put their experience into words and interviewer asks the significant questions to make the participants talk about crucial parts of their experience. As making meaning lies at the center of resolution of grief of mourners (Worden, 2018, p19), IPA can be seen as a limited methodology to grasp the meaning of loss in amputees' life. It can only be understood by narratives or life stories. However, each methodology chosen has their own limits to gather and analyze data to contribute the literature is a well-known adverse effect. Other than IPA, discourse analysis or narrative analysis might be useful for a better understanding amputation experience in terms of giving meaning to silences in conversations and also gathering a full life story to give their own unique meaning to their peculiar incident. Different methods can be used for future research. Besides, IPA aims not to obtain a representative sample but to give voice to how individuals experience a particular phenomenon.

From another perspective, special criteria for PG of individuals with limb loss should be reconsidered. Different than the loss of loved ones and grief processes, limb loss bringing a loss in body self which initially requires healing of body physically before reparation of psychological wounds. Worden (2018, p.22) picked the term "complicated mourning" rather than "abnormal grief" by pointing the importance of mourning as a process to get in varied phases and at varied pace not to focus on the stigma of feeling of grief. Therefore, time limit for mourning is a debatable issue. However, duration for possible diagnosis for prolonged grief of amputees should be reconsidered which was already a controversial issue for World Health Organization

(ICD-11) 6 months after loss, American Psychiatry Association (DSM-5) 12 months after loss and 6 months after loss for grief researchers. Further studies were necessary investigating the “normal” duration of grieving in amputees before diagnosing it as PG. In the studies focusing on amputees going back to their occupation, re-gaining the functionality, 2 years after amputation was taken as a cut-off point (Schoppen, et al., 2001). Functionality is an important criterion determining the diagnose of PG. Hence, 2 years duration post amputation to go back to work might provide a clue about completing grief and adjustment of amputees.

Additionally, this study demonstrated the importance of religious coping and further studies can focus on types religious coping and its effect on mental health of amputees. Changes in religious belief after amputation, level of religiosity and religion which is believed seem like an important question to be grasped for the prognose of rehabilitation process.

Moreover, amputees neglected as regard to the possibility of PG might have under the risk of unable to reach their state of well-being. Pomeran, Coudane, Dap, and Dautel (2020) demonstrated that amputees with complicated grief was found to be more likely to have neuroma resection or stump revision surgery. In the body-mind dualism, not only psychological conditions of individuals affected by body, the body might be affected due to detrimental effects of psychological distress. Prolonged grief cannot be treated and detected might engender the damage of rest of the body. Therefore, possibility of PG in amputation before reaching novel surgery decisions should be eliminated and the proper treatment should be provided if necessary.

4.7. Conclusion

The findings of the dissertation might be beneficial for the sake of better rehabilitation outcomes of amputees following post amputation. Amputation does not only bring physical and psychosocial adversities in one’s life, but it is also an experience of loss with inevitable grief. Diagnose of Prolonged Grief Disorder and grief therapy might be beneficial for ongoing disturbance of adjustment problems, perceived phantom limb pain, additionally for the possible elevation of physical complaints after surgery due to prolonged grief of amputees (Pomeran, et al., 2020).

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APPENDICES

A: DEMOGRAPHIC INFORMATION FORM

Bir uzuv kaybınız var mı? Evet () Hayır ()

Kaybınız birden fazla mı (Alan ya da parça olarak düşünebilirsiniz)?

Evet () Hayır ()

Bedeninizin hangi kısmını kaybettiniz? (mümkün oldukça detaylı yazabilir misiniz?)

Kaybınız ne kadar zaman önce gerçekleşti? (Birden fazla ise her birini yazınız.) (Ay ya da yıl olarak belirtebilirsiniz).....

Kaybım..... Beklenmedikti ()

Beklentikti ()

Kaybınızın gerçekleşmemesi için yapabileceğiniz bir şey ya da şeyler/belki birtakın önlemler olmuş olabileceğini düşünüyor musunuz?

EVET () ise nasıl önlenebilirdi?.....

Hayır ()

Protez kullanıyor musunuz?

Evet () ise uyum sağlamakta zorlandınız mı?.....

Hayır ()

Kaybınızla yeni bir uyum sağlamak için kaç defa operasyon geçirmek durumunda kaldınız?.....

Hangi nedenle uzvunuzu/bedeninizden parça kaybettiniz?.....

Güçük ağrınızın şiddetini işaretleyebilir misiniz?

0 1 2 3 4 5 6 7 8 9 10

Hiç yok

Orta Şiddet

Çok Şiddetli

Güçük ağrınızın sıklığı nedir?

Günde birkaç defadan fazla ()

Günde en az birkaç defa ()

Haftada bir defadan fazla ()

Haftada en az birkaç defa ()

Ayda birkaç defadan fazla ()

Ayda birkaç defa ()

Yılda birkaç defadan fazla ()

Yılda birkaç defa ()

Fantom ağrınızın şiddetini işaretleyebilir misiniz? (Fantom ağrı kesilip uzaklaştırılmış artık var olmayan bir uzuvda hissedilen kasılma, yanma ve batma niteliğindeki ağrılardır.)

0 1 2 3 4 5 6 7 8 9 10

Hiç yok

Orta Şiddet

Çok Şiddetli

Fantom ağrınızın sıklığı nedir?

Günde birkaç defadan fazla ()

Günde en az birkaç defa ()

Haftada bir defadan fazla ()

Haftada en az birkaç defa ()

Ayda birkaç defadan fazla ()

Ayda birkaç defa ()

Yılda birkaç defadan fazla ()

Yılda birkaç defa ()

Fantom ağrınızın özelliğini tanımlayabilir misiniz? (Birden fazla seçeneği işaretleyebilirsiniz)

Şiddetli ani ağrı saplanması ()

Hafif süreğen bir ağrı ()

Karıncalanma ()

Gıdıklanma ()

Diğer

Uzuv kaybınız sonrası bir rehabilitasyon programına katıldınız mı?

Evet ()

Hayır ()

Uzrunuzla birlikte sizce başka şeyler kaybettiniz mi?

Evet () ise başka neler?

Hayır ()

Genel Bilgiler

Cinsiyetinizi belirtiniz.

Kadın ()

Erkek ()

Kaç yaşındasınız?

Hangi şehirde yaşıyorsunuz?.....

Eğitim düzeyiniz

İlkokul mezunu ()

Ortaokul mezunu ()

Lise Mezunu ()

Üniversite Mezunu ()

Üniversite Öğrencisi ()

Yüksek Lisans Mezunu ya da Öğrencisi ()

Doktora ve Doktora Sonrası Öğrencisi ya da Mezunu ()

Çalışıyor musunuz?

Evet ()

Hayır ()

Mesleğiniz nedir?.....

Kaybınız sonrası meslek/iş değiştirmeniz gerekti mi?

Evet ()

Hayır ()

Kısaca önceki ve sonraki işinizden bahsedebilir misiniz?.....

Aylık hanenize giren ortalama geliri belirtebilir misiniz?.....

Düzenli egzersiz/spor yapıyor musunuz?

Evet ()

Hayır ()

Kaybınız sonrası psikolojik destek almak üzere yönlendirildiniz mi? (psikolog, psikiyatr, aile danışmanı, vb.)

Evet ()

Hayır ()

Kaybınız sonrası psikolojik destek aldınız mı? (birden fazla işaretleyebilirsiniz).

Psikiyatrik ilaç kullanımı ()

Psikoterapi ()

Aile danışmanlığı ()

Diğer ().....

Aldığınız profesyonel yardım/destek sizce faydalı mıydı?

Evet () Hayır ()

Araştırmanın diğer aşamalarına katılmak ister misiniz?

Evet () Hayır ()

Yanıtınız EVET ise size ulaşabileceğimiz bir e-posta adresi yazabilir misiniz?.....

Yanıtınız EVET ise size ulaşabileceğimiz bir telefon numarası yazabilir misiniz?.....

B: Prolonged Grief Scale (PG-13) – Revised for Amputees

1. Geçtiğimiz ay içerisinde, kaybınızın eksikliğini (özleyerek, hasret duyar gibi) ne sıklıkla duydunuz?

- Hiç
- En az bir kere
- En az haftada bir kere
- En az günde bir kere
- Günde birçok kere

2. Geçtiğimiz ay içerisinde, kaybınızla ilgili olarak ne sıklıkla duygusal ızdırıp, yoğun üzüntü ya da keder hissettiniz?

- Hiç
- En az bir kere
- En az haftada bir kere
- En az günde bir kere
- Günde birçok kere

3. Kaybınızın ardından en az 6 ay geçmesine rağmen, Soru 1 veya 2’ deki belirtilerin herhangi birini, “en az günde bir kere” olmak üzere yaşadınız mı?

- Evet Hayır

4. Geçtiğimiz ay içerisinde, size kaybınızı hatırlatan şeylerden ne sıklıkla kaçınmaya çalıştınız?

- Hiç
- En az bir kere
- En az haftada bir kere
- En az günde bir kere
- Günde birçok kere

5. Geçtiğimiz ay içerisinde, ne sıklıkla kaybınız nedeniyle afallamış, hayrete düşmüş ya da şaşkına dönmüş hissettiniz?

- Hiç
- En az bir kere

- En az haftada bir kere
- En az günde bir kere
- Günde birçok kere

AÇIKLAMA: AŞAĞIDAKİ SORULARI ŞU ANDA KENDİNİZİ NASIL HİSSETTİĞİNİZİ GÖZ ÖNÜNDE BULUNDURARAK YANITLAYINIZ.

6. Yaşamdaki rolünüze dair kafanız karışmışçasına sanki artık kim olduğunuzu bilmek gibi hissediyor musunuz?

Hiç Çok az Biraz Çok Oldukça çok

7. Kaybınızı kabullenmekte güçlük çektiniz mi?

Hiç Çok az Biraz Çok Oldukça çok

8. Bu kaybı yaşadığınızdan beri, başkalarına güvenmek sizin için zor oldu mu?

Hiç Çok az Biraz Çok Oldukça çok

9. Kaybınız nedeniyle buruk hissediyor musunuz?

Hiç Çok az Biraz Çok Oldukça çok

10. Artık hayatınıza devam etmenin (örneğin, yeni arkadaşlar edinmek, yeni ilgi alanları oluşturmak vb.) sizin için zor olacağını hissediyor musunuz?

Hiç Çok az Biraz Çok Oldukça çok

11. Bu kaybı yaşadığınızdan beri duygusal olarak hissizleşmiş gibi hissediyor musunuz?

Hiç Çok az Biraz Çok Oldukça çok

12. Bu kaybı yaşadığınızdan beri hayatın boş ya da anlamsız olduğunu, doyum vermediğini hissediyor musunuz?

Hiç Çok az Biraz Çok Oldukça çok

AÇIKLAMA: AŞAĞIDAKİ MADDEYİ SİZE UYGUN SEÇENEĞE İŞARET KOYARAK CEVAPLAYINIZ.

13. Sosyal, mesleki veya diğer önemli alanlar açısından işlevselliğinizde önemli bir azalma yaşadınız mı? (Örneğin evdeki sorumluluklarınızı yerine getirememek gibi)

Evet Hayır

C: Beck Depression Inventory (BDI)

Sayın katılımcı aşağıda gruplar halinde cümleler verilmektedir. Öncelikle her gruptaki cümleleri dikkatle okuyarak, **BUGÜN DÂHİL GEÇEN HAFTA** içinde kendinizi nasıl hissettiğini en iyi anlatan cümlenin başındaki sayıyı seçiniz. Eğer bir grupta durumunuzu, duygularınızı tarif eden birden fazla cümle varsa her birini daire içine alarak işaretleyiniz. Soruları vereceğiniz samimi ve dürüst cevaplar araştırmanın bilimsel niteliği açısından son derece önemlidir.

- 1- 0. Kendimi üzüntülü ve sıkıntılı hissetmiyorum.
1. Kendimi üzüntülü ve sıkıntılı hissediyorum.
2. Hep üzüntülü ve sıkıntılıyım. Bundan kurtulamıyorum.
3. O kadar üzüntülü ve sıkıntılıyım ki artık dayanamıyorum.
- 2- **0. Gelecek hakkında mutsuz ve karamsar değilim.**
1. Gelecek hakkında karamsarım.
2. Gelecekte beklediğim hiçbir şey yok.
3. Geleceğim hakkında umutsuzum ve sanki hiçbir şey düzelmeyecekmiş gibi geliyor.
- 3- 0. Kendimi başarısız bir insan olarak görmüyorum.
1. Çevremdeki birçok kişiden daha çok başarısızlıklarım olmuş gibi hissediyorum.
2. Geçmişe baktığımda başarısızlıklarla dolu olduğunu görüyorum.
3. Kendimi tümüyle başarısız biri olarak görüyorum.
- 4- **0. Birçok şeyden eskisi kadar zevk alıyorum.**
1. Eskiden olduğu gibi her şeyden hoşlanmıyorum.
2. Artık hiçbir şey bana tam anlamıyla zevk vermiyor.
3. Her şeyden sıkılıyorum.
- 5- 0. Kendimi herhangi bir şekilde suçlu hissetmiyorum.
1. Kendimi zaman zaman suçlu hissediyorum.
2. Çoğu zaman kendimi suçlu hissediyorum.
3. Kendimi her zaman suçlu hissediyorum.
- 6- **0. Bana cezalandırılmışım gibi gelmiyor.**
1. Cezalandırılabilceğimi hissediyorum.
2. Cezalandırılmayı bekliyorum.
3. Cezalandırıldığımı hissediyorum.

- 7- 0. Kendimden memnunum.
1. Kendi kendimden pek memnun değilim.
2. Kendime çok kızıyorum.
3. Kendimden nefret ediyorum.
- 8- **0. Başkalarından daha kötü olduğumu sanmıyorum.**
1. Zayıf yanların veya hatalarım için kendi kendimi eleştiririm.
2. Hatalarımdan dolayı ve her zaman kendimi kabahatli bulurum.
3. Her aksilik karşısında kendimi hatalı bulurum.
- 9- 0. Kendimi öldürmek gibi düşüncelerim yok.
1. Zaman zaman kendimi öldürmeyi düşündüğüm olur. Fakat yapmıyorum.
2. Kendimi öldürmek isterdim.
3. Fırsatını bulsam kendimi öldürürdüm.
- 10- **0. Her zamankinden fazla içimden ağlamak gelmiyor.**
1. Zaman zaman içinden ağlamak geliyor.
2. Çoğu zaman ağlıyorum.
3. Eskiden ağlayabilirdim şimdi istesem de ağlayamıyorum.
- 11- 0. Şimdi her zaman olduğumdan daha sinirli değilim.
1. Eskisine kıyasla daha kolay kızıyor ya da sinirleniyorum.
2. Şimdi hep sinirliyim.
3. Bir zamanlar beni sinirlendiren şeyler şimdi hiç sinirlendirmiyor.
- 12- **0. Başkaları ile görüşmek, konuşmak isteğimi kaybetmedim.**
1. Başkaları ile eskiden daha az konuşmak, görüşmek istiyorum.
2. Başkaları ile konuşma ve görüşme isteğimi kaybetmedim.
3. Hiç kimseyle konuşmak görüşmek istemiyorum.
- 13- 0. Eskiden olduğu gibi kolay karar verebiliyorum.
1. Eskiden olduğu kadar kolay karar veremiyorum.
2. Karar verirken eskisine kıyasla çok güçlük çekiyorum.
3. Artık hiç karar veremiyorum.
- 14- **0. Aynada kendime baktığımda değişiklik görmüyorum.**
1. Daha yaşlanmış ve çirkinleşmişim gibi geliyor.
2. Görünüşümün çok değiştiğini ve çirkinleştiğimi hissediyorum.
3. Kendimi çok çirkin buluyorum.
- 15- 0. Eskisi kadar iyi çalışabiliyorum.

1. Bir şeyler yapabilmek için gayret göstermem gerekiyor.
 2. Herhangi bir şeyi yapabilmek için kendimi çok zorlamam gerekiyor.
 3. Hiçbir şey yapamıyorum.
- 16- 0. Her zamanki gibi iyi uyuyabiliyorum.**
- 1. Eskiden olduğu gibi iyi uyuyamıyorum.**
 - 2. Her zamankinden 1-2 saat daha erken uyanıyorum ve tekrar uyuyamıyorum.**
 - 3. Her zamankinden çok daha erken uyanıyor ve tekrar uyuyamıyorum.**
- 17- 0. Her zamankinden daha çabuk yorulmuyorum.**
1. Her zamankinden daha çabuk yoruluyorum.
 2. Yaptığım her şey beni yoruyor.
 3. Kendimi hemen hiçbir şey yapamayacak kadar yorgun hissediyorum.
- 18- 0. İştahım her zamanki gibi.**
- 1. İştahım her zamanki kadar iyi değil.**
 - 2. İştahım çok azaldı.**
 - 3. Artık hiç iştahım yok.**
- 19- 0. Son zamanlarda kilo vermedim.**
1. İki kilodan fazla kilo verdim.
 2. Dört kilodan fazla kilo verdim.
 3. Altı kilodan fazla kilo vermeye çalışıyorum.
- 20- 0. Sağlığım beni fazla endişelendirmiyor.**
- 1. Ağrı, sancı, mide bozukluğu veya kabızlık gibi rahatsızlıklar beni endişelendirmiyor.**
 - 2. Sağlığım beni endişelendirdiği için başka şeyleri düşünmek zorlaşıyor.**
 - 3. Sağlığım hakkında o kadar endişeliyim ki başka hiçbir şey düşünemiyorum.**
- 21- 0. Son zamanlarda cinsel konulara olan ilgimde bir değişme fark etmedim.**
1. Cinsel konularla eskisinden daha az ilgiliyim.
 2. Cinsel konularla şimdi çok daha az ilgiliyim.
 3. Cinsel konular olan ilgimi tamamen kaybettim.

9. Sevinç ve kederlerimi paylaşabileceğim arkadaşlarım var.

1 2 3 4 5 6 7

10. Ailem ve arkadaşlarım dışında olan ve duygularıma önem veren bir insan var. (örneğin, flört, nişanlı, sözlü, akraba, komşu, doktor)

1 2 3 4 5 6 7

11. Kararlarımı vermede ailem (örneğin, annem, babam, eşim, çocuklarım, kardeşlerim) bana yardımcı olmaya isteklidir.

1 2 3 4 5 6 7

12. Sorunlarımı arkadaşlarımla konuşabilirim.

1 2 3 4 5 6 7

E: Brief Symptom Inventory

Aşağıda insanların bazen yaşadıkları belirtiler ve yakınmaların bir listesi verilmiştir. Listede ki her maddeyi lütfen dikkatle okuyun. Daha sonra o belirtinin sizi bugün dahil, son bir haftadır ne kadar rahatsız ettiğini yandaki kutulardan uygun olanının içini X işaretleyerek gösterin.

	Hiç	Biraz	Orta Derecede	Epey	Çok Fazla
	0	1	2	3	4
1. İçinizdeki sinirlilik ve titreme hali	0	1	2	3	4
2. Baygınlık, baş dönmesi	0	1	2	3	4
3. Bir başka kişinin sizin düşüncelerinizi kontrol edeceği fikri	0	1	2	3	4
4. Başınıza gelen sıkıntılardan dolayı başkalarının suçlu olduğu duygusu	0	1	2	3	4
5. Olayları hatırlamada güçlük	0	1	2	3	4
6. Çok kolayca kızıp öfkelenme	0	1	2	3	4
7. Göğüs (kalp) bölgesinde ağrılar.	0	1	2	3	4
8. Meydanlık(açık) alanlardan korkma duygusu	0	1	2	3	4
9. Yaşamınıza son verme düşünceleri	0	1	2	3	4
10. İnsanların çoğuna güvenilmeyeceği hissi0	0	1	2	3	4
11. İştahta bozukluklar	0	1	2	3	4
12. Hiç bir nedeni olmayan ani korkular	0	1	2	3	4
13. Kontrol edemediğiniz duygu patlamaları	0	1	2	3	4
14. Başka insanlarla beraberken bile yalnızlık hissetme	0	1	2	3	4
15. İşleri bitirme konusunda kendini engellenmiş hissetme	0	1	2	3	4
16. Yalnızlık hissetme	0	1	2	3	4
17. Hüzünlü, kederli hissetme	0	1	2	3	4
18. Hiçbir şeye ilgi duymama	0	1	2	3	4
19. Ağlamaklı hissetme	0	1	2	3	4
20. Kolayca incinebilme, kırılma	0	1	2	3	4
21. İnsanların sizi sevmediğine kötü davrandığına inanmak	0	1	2	3	4
22. Kendini diğerlerinden daha aşağı görme	0	1	2	3	4
23. Mide bozukluğu, bulantı	0	1	2	3	4

24. Diğerlerinin sizi gözlediği ya da hakkınızda konuştuğu duygusu	0	1	2	3	4
25. Uykuya dalmada güçlük	0	1	2	3	4
26. Yaptığınız şeyleri tekrar tekrar doğru mu diye kontrol etme	0	1	2	3	4
27. Karar vermede güçlükler	0	1	2	3	4
28. Otobüs, tren, metro gibi umumi vasıtalarla seyahat etmekten korkma	0	1	2	3	4
29. Nefes darlığı, nefessiz kalma	0	1	2	3	4
30. Sıcak, soğuk basmaları	0	1	2	3	4
31. Sizi korkuttuğu için bazı eşya, yer, etkinliklerden uzak kalmaya çalışma	0	1	2	3	4
32. Kafanızın bomboş kalması	0	1	2	3	4
33. Bedeninizin bazı bölgelerinde uyuşmalar, karıncalanmalar	0	1	2	3	4
34. Günahlarınız için cezalandırılmanız gerektiği düşüncesi	0	1	2	3	4
35. Gelecekle ilgili umutsuzluk duyguları içinde olmak	0	1	2	3	4
36. Konsantrasyonda (dikkati bir şey üzerinde toplama) güçlük/zorlanma	0	1	2	3	4
37. Bedenin bazı bölgelerinde zayıflık, güçsüzlük hissi	0	1	2	3	4
38. Kendini gergin ve tedirgin hissetme	0	1	2	3	4
39. Ölme ve ölüm üzerinde düşünceler	0	1	2	3	4
40. Birini dövme, ona zarar verme, yaralama isteği	0	1	2	3	4
41. Bir şeyleri kırma/dökme isteği	0	1	2	3	4
42. Diğerlerinin yanındayken kendinin çok fazla farkında olmak, yanlış bir şeyler yapmamaya çalışmak	0	1	2	3	4
43. Kalabalıklarda rahatsızlık duymak	0	1	2	3	4
44. Bir başka insana hiç yakınlık duymamak	0	1	2	3	4
45. Dehşet ve panik nöbetleri	0	1	2	3	4
46. Sık sık tartışmaya girme	0	1	2	3	4
47. Yalnız bırakıldığında/kalındığında sinirlilik hissetme	0	1	2	3	4
48. Başarılarınız için diğerlerinden yeterince takdir görmediğiniz düşüncesi	0	1	2	3	4
49. Yerinde duramayacak kadar tedirgin hissetme	0	1	2	3	4
50. Kendini değersiz görme, değersizlik duyguları	0	1	2	3	4
51. İzin verdiğiniz takdirde insanların sizi sömüreceği duygusu	0	1	2	3	4
52. Suçluluk duyguları	0	1	2	3	4
53. Aklınızda bir bozukluk olduğu fikri	0	1	2	3	4

F: Semi-Structured Interview Questions

- Kendinizi tanıtır mısınız?
- Kaybınız ne zaman gerçekleşti?
- Kaybınız nasıl gerçekleşti bahsedebilir misiniz?
- Ampütasyon sonrası güdük ağrılarınızdan bahsedebilir misiniz? (güçük ağrısı ampüte edilen bölgenin ağrısı ve acısıdır).
- Yaşamınıza halen etkileri varsa bahsedebilir misiniz?
- Ampütasyon sonrası fantom ağrılarınız olduysa bahsedebilir misiniz? (fantom ağrı artık olmayan uzuvun varmış gibi hissedilerek kaşınması, ağrması ve karıncalanması olarak tariflenebilir.)
- Kaybınızın tipi nedir?
 - Bu kayıp hayatınızı nasıl etkiledi?
- Kaç tane operasyon geçirdiniz?
 - Birden fazlaysa sebebi nedir?
 - Ameliyat sonrası günlük hayata dönmeniz için ne kadar zaman geçti?
 - Ameliyat süreçleri sizin için nasıldı?
- Kaybınız sonrası neler yaşadınız bahsedebilir misiniz?
 - Ne gibi süreçlerden geçtiniz?
 - Fizik tedavi aldınız mı?
- Ailenizde uzuv kaybı olan başka biri var mı? (Varsa bahsedebilir misiniz?)
- Aile yaşamınızda kaybınızla birlikte neler değişti?
 - Olumlu/olumsuz olanlardan da bahsedebilir misiniz?
- İş yaşamınızda kaybınızla birlikte neler değişti?
 - Olumlu/olumsuz olanlardan da bahsedebilir misiniz?
- Sosyal yaşamınızda kaybınızla birlikte neler değişti?
 - Olumlu/olumsuz olanlardan da bahsedebilir misiniz?
- Çevrenizdekilerin size bakışında değişiklikler olduğunu düşünüyor musunuz?
 - Varsa neler?
 - Sizin çevrenizdeki kişilere olan bakışınızda farklılıklar oldu mu?
 - Varsa neler?

- Pekçok kiři önemli yaşam olaylarından sonra yaşadıklarına bir anlam vermeye çalıřır. Amputasyonuzun/uzuv kaybınızı nasıl anlamlandırdığınızdan bahseder misiniz? (örneğin neden sizin başınıza geldi?)
- Kaybınız sonrası yaşadığınız psikolojik etkilerin halen devam ettiğini düşünüyor musunuz? (örneğin kabullenebildiniz mi kaybınızı?)
 - Evetse nasıl?
- Kendinize bakış açınız deęiřti mi?
 - Evetse nasıl?
- Amputasyon sonrası hayata bakış açınızda deęişiklik olduğunu düşünüyor musunuz?
 - Evetse nasıl?*
- Kaybınız sonrası duruma uyum sağlamanızı zorlařtırdığını düşündüğünüz neler var?
- Bu zorlukları atlatabildiğinizi düşünüyor musunuz?
- Kaybınız sonrası duruma uyum sağlamanızı kolaylařtırdığını düşündüğünüz neler var?
- Engellilik yaşamınızı nasıl etkiledi?
- Yeni yaşam koşullarınızı deęerlendirdiğinizde řu anki yaşamınız ile geçmiş yaşamınızı kıyaslar mısınız?

G: TURKISH SUMMARY / TÜRKE ÖZET

1. GİRİŞ

Yas, yaşamın her evresinde kayıpların kaçınılmaz sonudur. Yas literatürü çoklukla sevilen kişilerin ölümün olarak kaybına odaklanmış olmakla birlikte, ideallerin kaybı, boşanma ya da bir arkadaşın başka bir şehre taşınması gibi yaşantılar da kayıp olarak deneyimlenmektedir (Bildik, 2013; Jeffreys, 2011, Volkan, & Zintl, 2010). Bu nedenle de yas tepkileri gözlenebilmektedir. Kayıp sonrası süreci tanımlayan yas, yas tutma ve matem gibi terimler birbirinin yerine geçer şekilde kullanılabilir (Jeffreys, 2011). Bunlardan yas tutma, kayıp sonrası uyumu da kapsayan kişinin deneyimlediği süreci tanımlamak için kullanılır (Worden, 2018). Öte yandan, yas Shear (2017) tarafından tek bir tanıma indirgenmesi mümkün olmayan, zaman içinde değişen ve dönüşen, her kayba ve her kişiye özgü tarafları olan karmaşık ve çokbileşenli bir deneyim olarak tanımlanmıştır. Yas kültürlerarası çeşitlenir, karmaşık ve dinamik (Jeffreys, 2011). Matem ise, özellikle sevilen bir kişinin kaybı sonrası uyum sağlama süreçlerini kapsamaktadır (Worden, 2018).

Yas tepkileri duygusal, bilişsel, fiziksel duyumlar ve davranışsal tepkiler olmak üzere geniş bir kapsamdadır (Worden, 2018). Üzüntü, öfke, inkar, hem öleni suçlamak hem de kişinin kendisine yönelik suçluluk hisleri, kaygı, yalnızlık, yorgun düşme, çaresizlik, şok, boşluk hissi, özlem, kurtuluş ve özgürleşme, rahatlama, sersemlik, uyuşukluk, boğazda tıkanıklık, göğüste ağırlık, sese duyarlılık, kendinden uzaklaşma, boğulma hissi, nefes alamıyor gibi hissetme, kaslarda zayıflık, enerjisizlik, inkar, inamama, kafa karışıklığı, kayıpla fazlaca uğraşma, varmış gibi hissetme ve halüsinasyonlar yas tutanların deneyimlerinden bazılarıdır (Jeffreys, 2011; Worden, 2018). Yas tutma işi beklenenden uzun sürdüğünde ya da bir şekilde tamamlanamadığında, yas tutanın kayıpla uğraşı sosyal ve mesleki işlevsellikte azalmalara neden olmaktadır. Bu durum alanyazında komplike, gecikmiş, tamamlanmamış ya da uzamış yas olarak adlandırılmaktadır. Ölen kişiyle ilişkinin algılanan kalitesi ve yakınlığı, kaybın doğası, uzamış yas geçmişi, yas tutma

kapasitesi, kişilik özellikleri, sosyal ve kültürel faktörler, çoklu ya da peşisıra gerçekleşen kayıplar, karşılanmamış çocukluk ihtiyaçları uzamış yasa neden olabilir ve risk faktörleri olarak görülebilir. Yas daha çok klinik pratikte ele alınan bir konu olmasına rağmen, tanı el kitaplarında da dikkat çeken ve önem kazanan bir konu olmaya başlamıştır. Alandaki önemli psikiyatrik tanı kitaplarından olan DSM-5 (2013)'te “Kalıcı Karmaşık Yas Bozukluğu” tanı kodu ile ileri çalışma gerektiren durumlar olarak, Dünya Sağlık Örgütü'nün tanı el kitabı olan ICD-11 (2018)'de ise “Uzamış Yas Bozukluğu” olarak yerini almıştır. En güncel haliyle ise, DSM-5-TR (2022)'de “Uzamış Yas Bozukluğu” olarak adlandırılarak ölümden sonra yetişkinler için en az 12 ay, çocuk ve ergenler için en az 6 ay geçmesine rağmen, halen kayba yönelik yoğun özlem ve ölenin anılarıyla uğraşa eşlik eden kimlik kaybı hissi, ölenin inkarı, öleni hatırlatıcılardan kaçınma, ölümlle ilgili yoğun duygusal acı, gündelik yaşama uyumda zorlanmalar, boşluk hissi, ölüm sonrası gelen yaşamın anlamsızlığı ve yalnızlık hislerine ek olarak işlevsellikte bozulma ve de kültürel normlardan beklenenden uzun ve şiddetli matem gibi kriterlerle tanımlanmıştır.

Literatürde, birini kaybetmek yas tutanın bir uzvunu kaybetmesine benzetiliyor olsa da, şaşırtıcı bir şekilde uzuv kaybı sonrası deneyimlenen yas süreci iyi şekilde tanımlanmamıştır. Ampütelerin uzuv kaybı sonrası yas süreçleri nasıldır? Ampüteler de uzuv kaybı yaşamış bireyler gibi uzamış yastan muzdarip midir?

Uzuv kaybı, fiziksel, psikolojik, sosyal ve çevresel değişiklikleri beraberinde getiren yaşamı kökten değiştiren bir durumdur (Peirano, & Franz, 2012). Başka kayıplarda da olduğu gibi uzuv kaybı yaşayan bireyler de yas tepkileri deneyimleyebilir ve bu yeni duruma uyum sağlamalarına engel olan uzamış yastan muzdarip oluyor olabilirler. Aslında ampüteler en temelde yalnızca bir uzvu kaybetmezler, aynı zamanda “normal” birey kimliklerini de kaybederek engelli bir birey kimliğini edinirler. Ayrıca, beden bütünlüklerini kaybederek de umutsuzluk, algılanan kontrolde, öz-güvende azalma, inanç sistemlerinde sarsılma ve sosyal izolasyonla karşı karşıya kalmaktadırlar (Oğul, & Erden, 2005; Öznur, 2013). Bunlara ek olarak, uzuv kaybı sonrası ampütelerin ampütasyondan uzun yıllar sonra bile depresyon ve kaygı düzeylerinde artış olduğu (Mckechnie, and John, 2014; Uzun, et al., 2003), güdük ve fantom ağrılar yaşadıkları (Crawford, 2014; Hogan, ve ark., 2022) bilinmektedir. Bu nedenlerle, ampütelerin

ampütasyon sonrası uzun yıllar psikolojik zorluklar yaşamasında uzamış yasın da bir etkisi olup olmadığı sorusu önemli görünmektedir.

Özetlemek gerekirse, mevcut literatür göz önünde bulundurulduğunda, bu tez nicel ve nitel olmak üzere iki çalışmadan oluşan bir araştırma deseni ile gerçekleştirilmiştir. İlk çalışmada, uzamış yasın psikolojik belirtiler, algılanan güdük ve fantom ağrıların sıklık ve şiddetiyle ilişkisi incelenmiştir. İkinci çalışmada ise, uzamış yasın uzuv kaybı olan bireyler tarafından nasıl deneyimlendiği Yorumlayıcı Fenomenolojik Analiz (YFA) yoluyla incelenmiştir.

2. ÇALIŞMA 1

İlk çalışmada, ampütelerin uzamış yası incelenmeden önce, PG-13 ölçeğinin ampüteler için uyarlanmış versiyonunun uygun ve geçerli yorumlara olanak tanıyıp tanımadığını anlamak üzere yapı geçerliği ve iç güvenilirliği incelenmiştir. Açıklayıcı Faktör Analizi (AFA) yoluyla ölüm nedeniyle yakınlarını kaybedenlerden farklı olarak uzuvlarını kaybedenler için bu ölçeğin yapı geçerliğinin uygunluğu test edilmiştir. Bunu takiben, Cronbach alfa değerleri iç güvenilirlik için incelenmiştir. Son olarak ise, demografik değişkenlerin, ampütasyonla ilgili bilgilerin ve psikolojik değişkenlerin uzamış yas ile ilişkisi Pearson korelasyonlarına bakılarak incelenmiştir.

2.1. Yöntem

2.1.1 Katılımcılar

Çalışmanın verisi amputasyondan en az 6 ay sonra çeşitli nedenlerle (tıbbi, travmatik vb.) en az bir uzuv kaybı yaşayan 103 kişiden Qualtrics (çevrimiçi veri toplama yazılımı) ile hazırlanan çevrimiçi çalışma bağlantısına davet edilerek veriler toplanmıştır. Ayrıca, protez merkezinden ve Türkiye Bedensel Engelliler Spor Federasyonu'nun özel izniyle de çalışma için duyuru yapılmıştır. Toplamda 60 (% 58,3) ampute, kağıt-kalem yöntemiyle çalışmaya katılmış olup, örneklemin çoğunluğunu 84 (%81) erkek oluşturmaktadır. Amputelerin yaşları 18-74 arasında değişmekte olup, ortalaması 36.1 (SD = 14.1) dır.

2.1.2. Ölçüm Araçları

2.1.2.1. Demografik Bilgi Formu

Demografik Bilgi Formu arařtırmacı tarafından yař, cinsiyet, eđitim durumu, sosyo-ekonomik düzey, amputasyon düzeyi, ampütasyon nedeni, hem güdük hem de fantom ağrının algılanan sıklığı ve yoğunluğu gibi sorulardan oluşturulmuřtur.

2.1.2.2. Uzamıř Yas Ölçeđi (UY-13)

Prigerson ve arkadaşları (2009), uzamıř yasin en yaygın ve kabul gören belirtilerini ve ayrıca DSM-5 ve ICD-11 sınıflandırma sistemlerini göz önünde bulundurarak Karmařık Yas Envanteri'nden (Prigerson ve ark., 1995) oluřan 13 maddelik bir ölçek önermiřtir. UY-13, Uzamıř Yas Bozukluđunu teřhis etmeyi ve ayrıca semptomların yoğunluđunu belirlemeyi amaçlayan bir boyut ve beř kritere sahiptir. Maddelerin 11'i Likert derecelendirmesini içerir (günde 1-hiçbir zaman ile 5- günde birçok kere arasında deđiřir) ve 2 madde ikili seçimlidir (evet&hayır). Katılımcılardan arzulama, özleme, özlem duyma, üzüntü, řařırma, řok, rol karmařası, kaybı kabullenmede güçlük, başkalarına güvenememe, hayata devam edememe duygusu, uyuřukluk, boşluk ve anlamsızlık olmak üzere 11 maddede derecelendirmeleri beklenmektedir. Diđer sorular, semptomların süresini ve sosyal-mesleki işlevsellikteki bozulmayı deđerlendirmeye odaklanır. UY-13'ün Türkçe uyarlaması Iřıklı ve arkadaşları (2020) tarafından yapılmıř, geçerli ve güvenilir bulunmuřtur. İç tutarlılık .90 olarak bulunmuř ve faktör analizi ile tek faktörlü yapı dođrulanmıřtır.

Uzamıř yas teřhisi, zorunlu olarak bir kayıp ve işlevsellikte (sosyal, mesleki ve diđer alanlarda) bozulma gerektirir. Ardından ayırma kriteri (1. veya 2. soruya günde en az bir kez cevap verilmelidir), süre kriteri (en az 6 ay) ve biliřsel, duygusal ve davranıřsal belirtiler (4. sorudan 12. soruya kadar, 9 soru üzerinden en az 5 soru) UYB tanısı koyabilmek için günde en az bir kez veya daha fazla yanıt verilmelidir) karřılanmalıdır. Kriterler karřılanırsa, yanıtlayıcının bir ruh sađlığı uzmanı tarafından ayrıntılı olarak deđerlendirilmesi önerilir (Iřıklı, ve ark., 2020). UY-13 ölen kiři yakınlarına yöneltilen bir ölçek olduđundan, "kaybettiđim kiři" olarak geçen ifadeler bu tez için "kaybım" olarak revize edilmiřtir.

2.1.2.3. Beck Depresyon Envanteri (BDE)

BDE, yetişkinlerin depresyon düzeyi ve riskini değerlendiren bir öz-bildirim formu olarak 21 maddeden oluşmaktadır (Beck 1961). Envanterin çevirisi ve uyarlaması, Türk popülasyonunda geçerli ve güvenilir bir ölçek olduğunu göstermiştir (Hisli, 1989). Puanların artması depresyon düzeyinin ve riskinin arttığını göstermektedir. Bu çalışmada iç güvenilirlik (Cronbach Alfa değerleri) .95 bulunmuştur.

2.1.2.4. Çok Boyutlu Algılanan Sosyal Destek Ölçeği (ÇB-ASD)

Aile, arkadaşlar ve romantik partnerin sosyal desteğini değerlendiren 12 maddeden oluşan öz-bildirim formu olan ölçek Zimet ve arkadaşları (1988) tarafından geliştirilmiştir. Ölçeğin Türkçe uyarlamasında geçerli ve güvenilir olduğu Eker ve Arkar (1995) tarafından bulunmuştur. Puanların yüksek olması her alanda ve toplamda algılanan sosyal desteğin yüksek olduğuna işaret etmektedir. Bu çalışmada iç güvenilirlik (Cronbach Alfa değerleri) toplam puan için .92, alt ölçekler için .89 ile .93 arasında bulunmuştur.

2.1.2.5. Kısa Semptom Envanteri (KSE)

Ölçek, Belirti Tarama Listesi -90-R (SCL-90-R) ile oluşturulmuş, 53 maddelik genel bir psikopatolojiyi değerlendirmek için oluşturulmuş kısa bir öz-bildirim formudur (Derogatis, 1992). KSE Türkçe'ye uyarlanmış ve geçerli ve güvenilir bir ölçek envanteri olduğu görülmüştür (Şahin ve Durak, 1994). Kaygı, depresyon, olumsuz benlik, somatizasyon, hostilite olmak üzere beş boyutu vardır. Faktörlerin iç güvenilirliği (Cronbach Alfa değerleri) .63 ile .86 arasında değişmektedir.

2.1.3. Prosedür

Öncelikle Orta Doğu Teknik Üniversitesi İnsan Katılımcılar Etik Kurulu'ndan gerekli etik onay alınmıştır (bkz Ekler). Amputelerden hem çevrimiçi olarak hem de ortez ve protez merkezinde kağıt-kalem yöntemi kullanılarak gönüllü katılımcılardan veri toplandı. Daha sonra ham puanların SPSS-25'te analiz edilebilmesi için veriler sayısal verilere dönüştürülmüş ve planlanan analizler gerçekleştirilmiştir.

2.2. Sonular

Doęuřtan ortopedik engelli olan bireyler, uzuv kaybı 6 aydan az olan amputeler ve yarıda bırakılmıř ya da anlamlandırılması g geersiz veriler, veri setinden ıkarıldı. Hipotezler, 103 amptenin verileri kullanılarak test edildi.

2.2.1. Tanımlayıcı İstatistikler

alıřmaya ortez ve protez merkezlerinden 60 katılımcı kaęıt-kalem yntemiyle katılmıř, 43' ise online veri toplama yntemiyle elde edilmiřtir. Yař ortalaması 36.1 (SD = 14.1) olan 84 erkek ve 19 kadın vardır.

2.2.2. Arařtırma Sorularıda dair Bulgular

ncelikle, arařtırma sorusu iin gvenilir ıkarımlarda bulunabilmek iin UY-13'n psikometrik zellikleri incelenmiřtir. Bu nedenle Aımlayıcı Faktr Analizi yapılmıř ve Cronbach Alfa deęerleri incelenmiřtir.

2.2.2.1. UY-13'n Ampte rnekleme Faktr Yapısı ve İ Gvenirlięi

UY-13'n faktr yapısını belirlemek iin Temel Bileřen Analizi (PCA) yapılmıř, Varimax dndrme kullanılmıřtır. Kaiser–Meyer–Olkin (KMO) deęeri .88 olarak bulunmuřtur. Bartlett'in kresellik testi sonuları $X^2 = 616.87$, $df = 55$ ($p < .001$) olarak elde edilmiřtir. PCA sonuları, zdeęerleri 1'den byk olan iki faktre iřaret etmiřtir. İlk faktrn zdeęeri 6.26, ikinci faktrn zdeęeri 1.2 olduęu grlmřtir. Birinci faktr varyansın % 56.92'sini, ikinci faktr % 10.51'ini ve toplamda % 67.43'n aıklamıřtır. 7, 8, 11, 12. maddeler her iki faktre de ift pozitif olarak yklenmiř, geri kalan maddeler ise benzer řekilde her iki faktre yklenmiř, ancak ikinci faktre negatif yklenmiřtir. Ancak tm maddeler birinci faktrde daha yksek yklere sahiptir. Bu nedenle ampute rnekleminde bu lek iin tek faktrl zmn daha iyi olduęu dřnlmřtir. Benzer řekilde Trke UY-13'n uyarlanmıř versiyonunda da tek faktrl yapı belirlenmiřtir (Iřıklı ve ark., 2020),

Sonu olarak faktr yapısı tek faktre sabitlenmiřtir. Kaiser–Meyer–Olkin (KMO) deęeri .88 olarak bulunmuřtur. Bartlett'in kresellik testi sonuları $X^2 = 616.87$, $df =$

55 ($p < .001$) olarak görülmüştür. Faktörün özdeğeri 6.26 olup varyansın %56.92'sini açıklamaktadır. Faktör yükleri .61 ile .85 arasında değişmektedir.

UY-13'ün 11 maddesi için Cronbach alfa değeri .92 olarak bulunmuştur.

2.2.2.2. UY-13'ün Ampüte Örnekleme İncelenmesi

Yirmi altı amputenin (%25,2) psikiyatriste sevk için UY-13 kriterlerine uygun olduğu görülmüştür. Ayrıca 11 ampute (%42,5) birden fazla bölgede kayba sahipti. Amputasyondan bu yana geçen süre 6 ay ile 31 yıl arasında değişmekteydi ve yıl ortalaması 9.21 (SD = 9.73)'tı. Ayrıca, UYB tanısı alma olasılığı olan ampütelerin %96,2'si (N = 25) beklenmedik bir kayıp bildirdiği görülmüştür. Amputelerin %38,5'i (N=10) tıbbi nedenler, %26,9'u trafik kazası (N=7), %23,2'si (N=6) kaza ve %11,5'i (N=3) patlama nedeniyle uzuv kaybı yaşadığı bildirilmiştir.

2.2.2.3. UY-13 ile Demografik Değişkenlerin ve Psikolojik Belirtilerin İncelenmesi

UY-13'ün toplam puanları inceleme amacıyla hesaplanmış olsa da, UYB tanısı alma olasılığı olanlar sadece ölçüm araçları bölümünde özetlenen belirli kriterler ile belirlenebilmektedir.

UYB tanısı olasılığı ile güdük ağrısının şiddeti ($r = .25$, $p < .05$) ve sıklığı ($r = .22$, $p < .05$) ve ayrıca fantom uzuv ağrısının şiddeti ($r = .24$), $p < .05$) ve sıklığı ($r = .25$) arasında olumlu ve anlamlı bir ilişki olduğu görülmüştür. Ayrıca, amputasyondan bu yana geçen süre ile hem güdük ($r = -.29$, $p < .001$) hem de fantom uzvun ağrısının ($r = -.28$, $p < .001$) sıklığı arasında negatif bir korelasyon tespit edilmiştir. Öte yandan, UYB tanısı olasılığı ile kaybın algılanan doğası arasında bir ilişki olmadığı ($r = -.14$, $p > .05$) dikkat çekmiştir.

Psikolojik belirtiler ve UYB arasında anlamlı bir ilişki olmadığı görülmüştür.

Özetlemek gerekirse, UYB ve güdük ve fantom ağrısının sıklığı ve şiddeti arasında pozitif ve anlamlı bir ilişki olduğu, fakat psikolojik belirtiler ve UYB arasında anlamlı bir ilişki olmadığı görülmüştür. Ayrıca, amputasyon nedeninin önceden bilgi verilmiş tıbbi bir neden olmasından ya da bir kaza ya da patlama gibi beklenmedikliğinden

ziyade kaybın algılanan doğasının yani beklenmedik olarak alınılanmasının bir risk faktörü olarak görülebileceğine yönelik işaretler vardır.

3. ÇALIŞMA 2

Yas deneyimi, her bireyin kişisel geçmişine, geçmiş travma ve kayıp deneyimlerine, yası işleme kapasitesine, sosyal çevresine ve kültürüne özgü olduğundan; her ampute uzuv parçasının kaybını çok benzersiz bir şekilde yaşamaktadırlar. Birden fazla parçanın kaybı ve değişiklikleri dikkate alındığında; vücut parça(lar)ının kaybı, vücut bütünlüğünün kaybı, “normal” (normatif) vücut görünümü, “normal” kimlik ve ayrıca vücut parça(lar)ının yokluğuna uyum, protez, tekerlekli sandalye, engelli kimliğine uyum gibi aynı anda eşzamanlı yas süreçlerinin de içe içe geçmesi sözkonusudur. Her bireyin bu karmaşık süreci kendince yaşaması şartırtıcı olarak görülmemelidir. Bu nedenle, ampütelerin uzun süreli yas deneyiminin, bu spesifik fenomeni araştırabilmek için nitel yöntemlerle gerçekleştirilmesi daha iyi olacağı düşünülmüştür. Derinlemesine olay ve şeylerin anlamlarını anlayabilmek için nitel araştırmalara ihtiyaç olduğu bilinmektedir (Lune ve Berg, 2017). Amputelerde uzamış yas, yaşanan deneyimin net olarak tanımlanamadığı ve anlaşılamadığı bir olgu olduğundan, genellikle günlük yaşam deneyimlerine konu olan ve bireylerin yaşamlarında belirli bir öneme sahip olan verileri analiz etmek için Yorumlayıcı Fenomenolojik Analiz (YFA) uygun bir araç olduğu düşünülerek seçilmiştir Smith, Flowers, ve Larkin, 2022).

Smith'e (2004) göre, YFA yanıtlayıcıların kişisel deneyimlerini keşfetmeyi amaçlayan ve belirli bir yol ve deneyimlerine nasıl anlam verdiklerini idiografik (yani her bir vakanın ayrıntılı analizi), tümevarımcı (yani aşağıdan yukarıya analiz) ve sorgulayıcı (yani literatürle bütünleştirilmiş) bir yöntemdir. YFA, bu "uzak deneyime" sahip olanlar için deneyime doğrudan bir yol bulmanın imkansızlığını kabul ederek "deneyimi yakınlaştırmaya" çalışmaktadır (Smith, 2011). Ayrıca YFA, katılımcıların kaygılarını araştırmacıların gözünden dile getirmek olarak da açıklanabilmektedir (Larkin, Watts, & Clifton, 2006). YFA, hem yanıtlayanların hem de araştırmacıların iki ayrı dünya görüşünü içerdiğinden, çift yorumsal bir şekilde yürütülür; araştırmacıların yanıt verenlerin dünyasını yorumladığı görülmektedir (Smith, 2011). Smith (2004), YFA'yı araştırmacıların merakını başlatan ve deneyimlerini anlamaya

başlamalarına yardımcı olacak bir başlangıç noktası sağlayan bir araç olarak tanımlamıştır. Smith (2011a, 2011b)'in iyi YFA temeli için ilk girişimlerinden sonra, Nizza, Farr ve Smith (2021), geçen yıllarda yayımlanan YFA belgelerini değerlendirerek iyi, kabul edilebilir ve kabul edilemez olarak çok daha ayrıntılı üç kalite düzeyi ortaya koydu. Web of Science, Medline ve Psychinfo veritabanlarından 1996 ve 2008 arasındaki makaleleri inceleyen bu araştırmada *iyi bir YFA, odaklanmayı ve derinlik sunmayı, güçlü veriler ve yorumlamalar sunmayı ve okuyucunun ilgisini çekmeyi ve aydınlatmayı sağlamalıdır* olarak çerçevelendirilmiştir. Bu araştırmadaki YFA'nın tüm bölümlerinde bu kriterler dikkate alınarak analizler yapılmış ve raporlanmıştır.

3.1. Yöntem

3.1.1. Katılımcılar

Bu çalışmanın katılımcıları, Çalışma 1'e katılan gönüllü amputelerin iletişim numaralarının yardımıyla toplanmıştır. Hem uzamış yası olan hem de olmayan katılımcılar, Smith ve ark. (2022), sadece fenomeni yaşayanların değil, fenomenin her iki tarafının da daha iyi anlaşılmasını kolaylaştırdığını ileri sürmüştür. Örneğin, terapi ilişkisi olgusunu anlamak için terapistleri ve hastaları bir IPA araştırmasına dahil etmek örnek olabilir. Bu IPA'nın örnekleme, uzun süreli yası olan 3 ampute ve uzun süreli yası olmayan 3 amputeyi içermektedir. Katılımcılar en az 6 ay, en fazla 10 yıl önce ampute olmak, en az 18 yaşında olmak ve tek bacak amputasyonlu olmak kriterlerini karşıladı. Sosyal medya yardımıyla katılımcılara ulaşılması planlanmaktadır. Çalışma 1'deki kadın gönüllü katılımcı sayısının sınırlı olması ve katılanların Çalışma 2'nin bir parçası olmak konusunda istekli olmaması nedeniyle, tekil bacak amputasyonu ile tanışmayan bir kadın katılımcı, destek verebilmek için örneğe dahil edilmiştir. araştırmaya kadın sesi. Toplamda 6 kişi mülakata alındı. Örneklemin demografik özellikleri Tablo X'te yer almaktadır. Örneklem büyüklüğü 6 ila 10 katılımcı ise IPA yönergelerine uygun olacaktır. IPA, vakaların yoğun ve detaylı bir analizi olduğu için küçük ve homojen örneklem tercih edilmiştir (Smith & Osborn, 2003).

3.1.2. Prosedür ve Verilerin Analizi

Çalışma için öncelikle ODTÜ İnsan Denekler Etik Kurulu'ndan etik onay alındı. Yarı yapılandırılmış görüşmeler yapılmıştır (bkz. Ek F). İlk çalışmada demografi zaten alındığından, her görüşme kim oldukları gibi giriş soruları ile başladı. Bu ısınmanın ardından amputasyonun hikayesi ve onlar için amputasyonun anlamı (yani sizce bu size ne oldu?) sorgulandı. Araştırmacı görüşmeleri kelimesi kelimesine yazıya dökmüştür. Her görüşme dinlenmiş, dikkatlice tekrar okunmuş ve bu notları temalar halinde birleştirebilmek için betimsel olarak notlar alınmıştır. İlk temaları kümelemek için prosedür her durum için ayrı ayrı tekrarlanmıştır (Smith, Flowers, & Larkin, 2009). YFA, transkriptlere ilişkin üst temaların ve alt temaların ortaya çıkmasını kolaylaştırmıştır. Görüşmeler 53 ile 98 dakika arasında sürmüştür.

3.2. Bulgular

YFA'ya göre dört üst tema ortaya çıkmıştır: 1) yaşam ve ölüm veya amputasyon, 2) uzuv kaybının maliyetiyle hayatta kalmak hayattaki sınav ve uzvun yokluğu olmak üzere iki alt temaya sahiptir ve, 3) hayata tutunma ve 4) hala orada.

3.2.1. Yaşam & Ölüm ve Ampütasyon

Bu üst tema, yaşam ve ölüm arasında duran amputasyonun anlamının altını çiziyor. Uzuv kaybı pahasına hayatta kalmak ve hayattaki sınav olmak üzere iki alt teması vardır. Ampütasyon kararı, kaza ve patlamalardan ziyade özellikle sağlıkla ilgili sorunlarda ölümün söz konusu olduğu bir dönemde hayatta kalabilmek için çoğu zaman zorunlu bir tercih olarak görülebilmektedir. Bu seçim bazen bir doktor tarafından önerilip gerekli görüldüğü gibi bazen de yaşanmış bir kayıpla yüzleşmek zorunda kalınabilmektedir. Ama şimdi ampütasyon sahnede ölümün yerini almış olsa da hayatın olağan düzenini bozarak bir süre daha ön planda kalıyor.

3.2.1.1. Uzvunu Kaybetme Maliyetiyle Hayatta Kalmak

Bu alt tema, amputasyonu getiren ve uzuvlarına veda eden durumları içerir. Ölümle yaşam arasında bir noktada, dayanılmaz ağrı ve uzvun işlev bozukluğu veya zorlukları nedeniyle uzvun kesilmesi ve bırakılması gerekli hale gelir. Sabri dışında beş katılımcı, riskli sağlık sorunları nedeniyle zorunlu olarak uzvunu kesme kararı aldı.

Yeni bedensel sınırlar getirecek olan bu veda, aynı zamanda daha sağlıklı bir beden ve yaşama ölümden daha yakın bir seçimdir. Ancak bedel, özellikle amputasyon için sağlıkla ilgili sorunları olanlar için bundan vazgeçmek.

Beş katılımcı, aşırı derecede çektikleri acıdan kurtulmak ve ölüm ya da hayatlarını dayanılmaz hale getiren sağlıklı durumlarını kaybetme olasılıklarını azaltmak adına uzuvlarının bedelini ödemeye razı oldular. Amputasyon kararı verirken yaşadıkları acının boyutu, ölüme tanık olmaları, uzuvlarının çürümesi ve geride kalanları da göz önünde bulundurmaları kararlarını kesinleştirmeye yöneltti. Uzuv kaybetmek, sadece acıdan ve ölümden kurtulmak değil, aynı zamanda hız, ona sahip olmanın hatırlatıcısı ve hatırasıydı. Ampute edilme nedenlerinin meşruluğuna rağmen, zorunlu maliyet kolayca kabullenilemeyecek kadar sarsıcıydı ve amputasyon sonrası yaşananlar, neyin kaybedildiğinin ve perhizin nasıl kabul edileceğinin gerçekliğiyle yüzleşmek için zamana ihtiyaç duyuyordu.

3.2.1.2. Hayattaki İmtihan

Ampütasyon gerçekleşikten sonra hayat, öncesi ve sonrası olmak üzere keskin bir şekilde iki döneme ayrıldı ve hayata devam edebilmek için anlamlandırmayı gerektiriyor. Dolayısıyla bu alt tema, Allah'a olan inançlarının veya hayatla olan bağlarının sadakatini ve bağlılığını denemek için Allah'ın verdiği bir imtihan olan ampütasyona verilen anlamlara odaklanmaktadır.

Beş katılımcı, ampütasyonlarına dini bir anlam yüklediler ve inançlarını, kendilerini özel ve önemli hissetmek ve öfke ve isyan duygularını hafifletmek için bir başa çıkma mekanizması olarak kullandılar. Ancak Erdem, bunun, içsel kontrol odağını bulmayı kolaylaştıran bir Tanrı veya evren tarafından kendisine verilen bir sınav olduğu fikrini reddetti. Amputasyon o kadar zorlu bir yaşam olayı ki, ampüteler yaşadıkları haksız duruma anlam verebilecek her şeye gücü yeten bir figüre ihtiyaç duyuyorlar ve vücut bölgelerine veda etmek zorunda kalıyorlar. Sonuç olarak, bir vücut parçasını kaybetmek, hem psikolojik hem de fiziksel olarak yüzleşmek ve işlemek ve sindirmek için sarsıcı bir yaşam olayıdır; Dinler ve maneviyat hayata dair cevaplar verdiği için, ampute'ler bu zorlayıcı yaşam durumundan sonra ondan yararlanmaya çalıştılar.

Çoğunlukla bunun neden olduğunu sorgulamamayı, özellikle de Allah'la olan iyi iç ilişkilerini korumak için topu inanca atmayı tercih ettiler.

3.2.2. Uzuvun Yokluğu: “Hayat Alt Üst Olur”

Amputasyon, ampütenin yaşamında birçok somut ve soyut kayıp ve değişikliği aynı anda beraberinde getirir. Bu nedenle bu üst tema, iş kaybı, evlilik ve eş kaybı, işlev kaybı ve normal insan kimliği ve engellilik ve bütünlüğün kaybı ile yeni kimlik kazanmayı içeren uzuv kaybına ek olarak kayıplara odaklanmaktadır; yetersizlik, özlem, öfke, reddedilme ve inkar gibi yoğun/kararsız duygular.

Özellikle sağlık sorunları gibi nedenlerle amputasyonun gerekliliği düşünülse de; amputasyon veya sakatlık olasılığı varsayılan olarak beklenen bir olasılık değildir. Belki de insanın kırılğan, kolayca kırılabilen ve hiçbir hazırlık yapmadan hayatını alt üst eden bir canlı olduğunu inkar ettiklerinde ortaya çıkıyor.

Özetlemek gerekirse; yetenek, iş ve eş ve evlilik kaybı, sevdiklerin algılanan desteğinin kaybı, gerçekle ve iç dünyayla temas ve güven kaybı, uzuv kaybına ek soyut kayıplar olabilir. Amputasyon kişinin hayatında birçok değişikliği aynı anda beraberinde getirirken, romantik ilişkilerden otorite figürlerine kadar hayatın pek çok alanına yoğun ve kararsız duygular yayılır.

3.2.3. Hayata tutunmak

Bu üst tema, proteze uyum, ruhsal aydınlanma, yeni meslek, yeni ilişkiler geliştirme ve desteklenerek ilişkileri geliştirme, yeni ilişkiler geliştirme gibi amputelerin yaşamlarını sürdürebilmeleri için uyum sağlamalarını ve yaşamlarındaki değişiklikleri kolaylaştıran faktörleri içerir. hobiler, gelişmiş benlik kavramı ve dünya kavramındaki değişiklikler.

Tüm katılımcılar başlangıçta zor olsa da protez kullanımını ayarladıklarını beyan ettiler. Doktorlar, kalan yara izinin/ağrının iyileşmesi için zaman tanımak için ameliyattan en az 6 ay sonra protez kullanmayı önermektedir. Protez ile yürümeyi öğrenmek, yeni doğmuş bir bebek gibi yeni hayatlarının başlangıcı olabilir ve hayata tutunmak, amputasyondan önce mümkün olduğu kadar yürüyebilmek ve fonksiyonlarını yerine getirebilmek için yedek bir bacakla başlar.

Sonuç olarak, tüm katılımcılar yaşamlarını devam ettirebilmek için fiziksel ve psikolojik desteklerden ve hayata bakış açılarındaki değişikliklerden bahsetmiştir. İlk olarak, yeniden mobil olmanın yollarını buldular; protez ve akülü tekerlekli sandalye hem sevdiklerimizin desteğiyle hem de toplumla birlikte. Mevcut ilişkilerin iyileşmesine ek olarak, yeni ilişkilerin geliştirilmesi hayata tutunmak için yeni nedenler olabilir. Değişime uyum, kendilerine ve dünyaya yeni bir bakış açısı sağladığından, gelişen benlik algısı ve dünyadan bahsetmişlerdir. Bazılarının hala onlara meydan okuduğu tüm zorluklardan sonra, uyum her ampüte için çok özeldi.

3.2.4. Hala orada

Tüm katılımcılar amputasyondan yıllar sonra bile hayalet ağrı yaşadıklarını beyan ettiler. Fantom ağrısının yaşanmış deneyimi kişiden kişiye değişir. Bazen bir sıyrık gibi bazen de bir eziyet gibi geliyor beyinlerinin sanki hala oradaymış hastalığı ve acıları simgeliyormuş gibi ya da Yağmur'un sözleriyle “Oscar ödülleri” içinmiş gibi uzvun hala durduğu hissine kapılması. Orası. Tüm bu hayalet ağrı deneyiminin gün geçtikçe azaldığı anlatılırsa, uzuv kaybı ağrısının da bireylerin alıştığı bir süreç olduğunu sembolize edebilir. Ancak aynı zamanda bu çalışmadaki hiçbir amputenin onlardan kurtulma şansı bulamamış olması, uzuv kaybının acısının da hiçbir zaman tamamen bitmeyeceğinin simgesi olabilir.

Sonuç olarak, her ampütenin fantom ağrısı, amputasyona içsel anlamlarına göre subjektif bir anlam verdi. Mesela Sadık ve Neriman'a hastalıklarından kıvrılırken eski acılarını hatırlattı. Ayrıca Yağmur, eksikliğini uzuv kaybını kabullenemeyeceği şeklinde yorumladı. Aksine Sabri, amputasyonuna pek anlam yüklediği gibi onlara da pek anlam yüklediğini beyan etmiştir.

4. TARTIŞMA

4.1. Bulguların Genel Gözden Geçirilmesi

Uzuv kaybı, aynı anda fiziksel, psikolojik, sosyal ve çevresel değişiklikler getiren yaşamı değiştiren bir durumdur (Peirano ve Franz, 2012). Bu tez hem ampütelerde PG'nin varlığına dair genel bir temel kanıt sağlamakta, hem de amputasyon sonrası ampütelerin uzamış yas ve adaptasyon sürecine yönelik olmasa da yas konusuna

özgün, derinlemesine, idiografik bir bakış açısı sunmaktadır. araştırılacak Aslında amputelerin uzayan yas deneyimlerini incelemek istedim, uzuv kaybına ek olarak birden fazla kaybın aynı anda olduğunu söylemek yanlış olmaz; amputasyon sonrası iş, eş ve engelsiz kimlik kaybı, bağımsızlık ve beden bütünlüğü iç içe geçmiş ve psikolojik yüklerini birbirinden ayırt etmek güçtür. Her bir kayıp, ampütelerin yas deneyimine ve psikolojik sıkıntılara benzersiz şekilde çeşitli şekillerde katkıda bulunur. Dahası, her bireyin yaşamlarını sürdürmek ve yaşadıkları kederi ve travmatik deneyimi işlemek için kendine özgü başa çıkma yolları ve uyum sağlama kapasitesi vardır. Sadece sıkıntı değil, bu keskin olayla birlikte bir büyüme de olabilir. Öyleyse; uzuv kaybı deneyimi oldukça heterojendir ve bireylerin yas tutma kapasitelerine ve kişisel geçmişlerine özgüdür. Ampütasyonun nedeni benzer faktöre bağlı iken, ampütelerin tepkileri ve psikolojik prognozları çeşitlenmiştir. Bu çeşitliliğe rağmen, katılımcılar arasında ampütasyonun nedeninden ve kesilen uzantılardan ve hatta ampütasyondan sonra geçen yıllardan bağımsız olarak ortak düşünce ve duygular ve yaşanmış deneyimler de vardı. Başka bir deyişle; Sağlık sorunları nedeniyle hayatta kalmak için zorunlu bir seçim ya da bir trafik kazası nedeniyle ani bir kayıp olsa da amputasyon, hayatın olağan akışında uyum sağlamak için ara vermek ya da mevcut işten vazgeçmek gibi pek çok değişikliği beraberinde getirir. yeni doğmuş bir bebek gibi protezle yürümeyi öğrenmek. Ayrıca kesilen uzvun sayısı ve yerinden bağımsız olarak eksiklikle karşılaşmak kaçınılmazdır. Bunlara ek olarak, hayalet ağrı geçen yıllara rağmen ampütasyonun kendisini hatırlatabilir.

4.2. Ampütelerde Uzamış Yasa Dair İşaretler

Çalışma 1'in bulguları, uzvunu kaybeden bireylerin uzun süreli yastan muzdarip olabileceğini göstermiştir. Türkçe PG-13 uyarlamasında olduğu gibi PG-13 tek faktörlü yapıya sahiptir. Açımlayıcı Faktör Analizi (AFA) sonuçları uygun bulunmuş ayrıca PG-13'ün ampute örneklem üzerindeki iç güvenilirliği uygun bulunmuştur (Büyüköztürk, 2002). Ayrıca bulgular, PG-13'ün Türkçe'ye uyarlaması ve özgün ölçek ile de uyumludur (Işıklı ve diğerleri, 2020).

Çalışma 1'deki katılımcıların %25,2'si PG-13 kriterlerine uyuyor. Pomas, Coudane, Dap ve Dautel (2020), Fransa'daki retrospektif tasarım çalışmalarının bulgularına göre, travmatik üst ekstremité ampute hastalarının %38'inin komplike yas yaşadığını

bildirdi. Yüzdeler arasındaki fark, seçilen araştırma deseni ve seçilen ölçme aracı ve örnekleme yöntemleri ile açıklanabilir. Ölçme ve sistematik örnekleme olarak retrospektif çalışma tasarımı olan Inventory of Complicated Grief'i (ICG, Prigerson ve diğerleri, 1995) kullanırken; Çalışma 1'de kesitsel desen, PG-13 ve uygun ve kartopu örnekleme kullanılmıştır. Örnekleme için spesifik el kayıplarından farklı olarak, Çalışmada kaybın alanı ve seviyesinden çok uzuv kaybı ve sayısına odaklandım. 1, kayıpların sayısı uzayan yasta katkıda bulunabilir. Öte yandan, hem kağıt-kalem hem de çevrimiçi çalışmayı dolduran ve ulaşan katılımcılar, ortez ve protez merkezlerinde protez aramak ve internet tabanlı araştırmalara katılmak için zaten daha işlevsel ve yeni durumlarına adapte olmuş kişiler olabilir. Bu nedenle uzun süreli yas yaşayan amputelerin oranı, amputelerin psikolojik sıkıntılarına ve rehabilitasyon süreçlerine ışık tutmak için uzun süreli yasin rolüne odaklanan öncü bir çalışma olarak yorumlanabilir.

4.3. Uzuv Kaybı Deneyimi

4.3.1. Ampütasyonun Anlamı

Sağlık sorunları durumunda uzuv kaybı ortaya çıktığında; kanser, damar hastalıkları gibi; patlamalar, kazalar; amputeler büyük olasılıkla ölme olasılığı ile karşı karşıyadır. Bu nedenle, amputasyon, vücudun geri kalanının hayatta kalmasına izin verebilmek için bazı bölümlerin ölümüne izin vererek, yaşamla ölüm arasında orta bir seçim olarak görülüyordu. Ampütasyona sahip olmak, hem hayatta kalmaya hem de ölüme yaklaşmaya dair yoğun, kararsız duygular getirir. Mental Bozuklukların Teşhis ve İstatistik El Kitabı, 5. Baskıya (DSM-5) göre, Travma Sonrası Stres Bozukluğu (TSSB) tanısının "A" ölçütü, "doğrudan" "gerçek veya ölüm tehdidi veya ciddi yaralanma veya cinsel şiddet" yaşamaktır (APA, s.271). Travma, yaşananlara verilen yoğun fiziksel ve psikolojik tepkiler olarak da tanımlanabilir (Madde Bağımlılığı Tedavi Merkezi, 2014). Travma literatürüne göre ölme ve vücut bütünlüğünü kaybetme olasılığı travmatik olarak yaşanabilmektedir. Bu nedenle her amputasyon, vücut bütünlüğünün kaybı ve çoğu durumda ölüm olasılığı ile karşı karşıya kalması nedeniyle travmatik olarak da değerlendirilebilir. Travma, amputeler için olası bir tanı olarak düşünülmelidir. Ancak Phelps, Williams, Raichle, Turner ve Ehde (2008), literatürde travmatik yaralanmalar ve yaşamı tehdit eden durumlar ile ilgili birçok

çalışma olmasına rağmen, travmatik olmasına rağmen ampute popülasyonun TSSB'sine odaklanan çalışma sayısının sınırlı olduğunu eleştirmişlerdir. doğa. Ayrıca uzuv kaybının travmatik tarafı ile kayıp deneyiminin getirdiği yas birbirinden ayrı düşünülemez. Araştırmalar, çift yönlü etkileşime giren semptomlar arasında bir örtüşme olmasına rağmen, PG'nin kayıpla aşırı meşgul olma açısından TSSB'den farklı bir kavram olduğunu göstermiştir (Djelantik ve diğerleri, 2020; Wen ve diğerleri, 2022). Yaşananlara anlam vermek, travmaların, kayıpların ve uzayan yasin sindirilmesinin önemli bir parçasıydı (Worden, 2018). Stroebe, Schut ve Finkenauer'e göre (2001 aktaran Worden, 2018, s. 19) “travmatik yas” olarak adlandırılan şiddet olaylarında yas ve travma çoğunlukla çift yönlü etkileşebilir. Ancak, uzvunu kaybetmenin travmatik doğasını anlamak bu tezin kapsamı dışındaydı, katılımcıların yas süreçlerine karışmış olabilir. Yarı yapılandırılmış sorular ampütasyon deneyiminin travmatik tarafını anlama konusunda eksik olsa da; travma ve travma sonrası büyüme, uzuv kaybına uyum ve uyum sürecinde bir konu haline geldi (bkz. *Uyum ve büyüme*).

4.3.2. Uzun Yokluğuyla Yüzleşme

İç içe geçmiş yas süreçlerini getirerek uzun süreli yas olasılığını artıran ek kayıplar ve değişiklikler. Yaşamın alt üst olması, amputelerde ortak bir özellikti, psikososyal uyumu etkileyebilirdi. Başlangıçta, ampütasyon, yetersizlik ve uzvun ve eski yaşamın ve yaşanmış deneyimlerin eksikliğini getiren herkes için bir yetenek kaybıydı. Sonuç olarak, özellikle iş sahibi olan amputelerin mesleklerini değiştirmek zorunda kalabilmeleri, amputelerin işlevselliğini, uyumunu ve psikososyal iyilik halini tehlikeye sokan mesleki, buna ek olarak ekonomik bağımlılığın kaybolmasına ve para sıkıntısına maruz kalmasına neden olmuştur.

Schoppen ve arkadaşları (2001), Hollanda popülasyonunda alt ekstremitte ampütelerinin %78'inin ampütasyondan sonraki 2 yıl içinde amputasyona bağlı nedenlerle çalışmayı bıraktığını ortaya koydu. Ayrıca alt ekstremitte amputelerinin %22-67'si aynı işine devam ederken, geri kalanı iş değiştirmek zorunda kalmıştır. Amerika'da yapılan başka bir çalışmada, üst ekstremitte amputelerinin %29'unun iş değiştirdiği ve bunların yaklaşık %61'inin halen ulusal nüfus ortalamasının altında olmasına rağmen halen çalışmakta olduğu saptanmıştır (Lee, et al., 2022). İşe dönüş oranı birçok araştırmaya göre yaklaşık %66 (Bkz. inceleme Burger, & Marinček,

2007), Millstein, Bain, & Hunter'a (1985) göre %89 ve Schoppen ve arkadaşlarına göre (2001) %79 olarak bulunmuştur.). Çelişkili sonuçlar, örneklem büyüklüğünün küçük olmasıyla ilgili olabilir ve araştırmaya katılmaya istekli olan amputelerin daha işlevsel ve iyilik hali yüksek olanlar olabilir. Eğitim düzeyi, fiziksel olarak daha az güç gerektiren işlerin gerekliliği, hayalet uzuv ve güdük düzeyi ve çoklu amputasyonlar, amputasyon yaşı, protez kullanımı, uzun mesafe yürüyebilme, iş hayatına dönüşü etkileyen faktörlerdir (Burger, & Marinček). , 2007; Lee ve diğerleri, 2022; Millstein, Bain ve Hunter, 1985; Schoppen ve diğerleri, 2001). Öte yandan, gazi örnekleme eğitimi, yıllık hane geliri ve engellilik, ağrıdan yararlanma düzeyi çalışma durumu ile ilişkili bulunurken amputasyon düzeyi, protez kullanımı işe dönüş ile ilişkili bulunmadı (Hawley ve ark., 2022). . Bu çalışmada Sadık işini değiştirip tekrar işe dönmek zorunda kalmıştır, Erdem zaten engelli olarak çalışmaktadır, Gürol çalışmayı bırakmıştır ve Sabri aynı işine devam etmiştir, Yağmur çalışmayı düşünmemektedir ve Neriman daha önceden çalışmayı planlamaktadır. o değildi. Araştırmalar, erkeklerin işlevsellik (REF) ile ilgili endişeler geliştirme olasılığının daha yüksek olduğunu, kadınların ise çoğunlukla vücut imajlarıyla ilgili endişeleri olduğunu göstermektedir (Ward Khan, O'Keeffe, Nolan, Stow ve Davenport,2019). Bu distribüsyonda erkekler mesleki ve maddi kaygılarından, Yağmur ise beden imajı kaygılarından bahsediyordu.

4.3.3. Uyum ve Büyüme

Amputasyon, ampütenin bağımsızlığını, hareketliliğini, esenliğini ve yaşam kalitesini etkiler (Murray ve Forshaw, 2013; Torbjörnsson, ve diğerleri, 2022). Ancak Volkan ve Zyntl'e (2010) göre, yas tamamlanabilirse her kayıp büyüme ve yenilenme için bir araç olabilir. Klinik uygulamada kayıp, yasin ötesinde kavramsallaştırılabilir ve travma sonrası büyüme potansiyeli ile ele alınabilir (Klurfeld, Buqo, Sanderson, & Ward-Ciesielski, 2020). Ardından, ampute yanıtlayıcıların büyümesini açıklamak için travma sonrası büyüme literatüründen yararlanılmıştır.

Her şeyden önce protez kullanmak, kaybedilen uzvun ve fonksiyonlarının telafisiydi. Amputasyon ve protez kullanımına olumlu uyum, hareketliliğin, bağımsızlığın ve öz yeterliliğin yeniden kazanılması açısından rehabilitasyonun önemli bir parçasıdır. Sinha, van den Heuvel ve Arokiasamy (2014), günlük protez ve yardımcı cihaz

kullanımının amputasyon ve protezi ayarlamak için en önemli faktörler olduğunu göstermiştir. Ayrıca, protezin işleyişinden orta düzeyde memnuniyetin, orta düzeyde psikososyal uyum ve sadece atletik faaliyetler dışında fonksiyonel ve sosyal faaliyetlerde kısıtlanmama ile ilişkili olduğunu bildirmişlerdir. Torbjörnsson ve meslektaşları (2022), protez kullanan amputelerin tekerlekli sandalye kullanmaya kıyasla yaşam kalitelerinde daha fazla artış olduğunu bulmuşlardır; ancak protez kullanmayanların bir yıllık takibin ardından yaşam kalitesinde önemli bir değişiklik görülmedi.

İkincisi, amputasyon sonrası hayatlarındaki olumlu gelişmelerden bahsedilen amputeler. Bunlar mevcut ilişkilerin daha iyi takdir edilmesi ve yeni bağlar edinilmesi, yeni hobi ve uğraşlar edinilmesi, ruhsal aydınlanma, hayata ve insan ilişkilerine bakış açısının genişlemesi, benliğinin diğer yönlerini keşfetmesi ve olgunlaşmasıdır. Tedechi ve Calhoun'a (1996, 2004) göre bireyler, travmatik bir deneyimden sonra kendiliklerinde algılanan değişiklikler, başkalarıyla ilişkilerde değişen anlayış ve değişen yaşam felsefesi olmak üzere 3 alanda daha iyi bir kişisel gelişime ulaşabilirler. Daha sonra bu geniş alanlar, başkalarıyla ilişki, yeni olanaklar, kişisel güç, yaşamı takdir etme ve maneviyat olarak beş kategoriye ayrıldı. Benzer şekilde, erkek gazilerin eşleri, güçlenen aile bağları ve bağları açısından kocalarının hayatındaki değişikliklere tanık olduklarını; hayata daha fazla değer verme ve hayata bakış açısı; yeni kariyer ve eğitim fırsatları; bir kişi olarak daha güçlü, daha dayanıklı; ve amputasyondan sonra yeni ilişkiler, arkadaşlar ve bağlantılar kurmuştur (Bartone ve Bowles, 2021).

4.4. Tezin Önemi

Bir uzuv veya organ kaybından sonra uzun süreli yas şaşırtıcı bir şekilde iyi belgelenmemiştir (Pomeras, et al., 2020). Bu nedenle bu tez, amputelerde PG'nin izine dair kanıtlar sunarak literatürdeki boşluğu doldurmayı amaçlamıştır. Çalışma, amputelerde uzun süreli yaşlara odaklanan bir öncü olarak kabul edilebilir.

Her şeyden önce, amputeler, sevdiklerini kaybeden bireylere göre uzun süreli yastan daha fazla muzdariptirler ve bu da yas danışmanlığının rehabilitasyon programlarında önemli bir role sahip olabilir. Ek olarak, bu tez kalıntı ve hayalet uzuv ağrısı ile PG arasındaki ilişkiye dair kanıtlar sunmaktadır. Özellikle hayalet uzuv ağrısı ve uzuv

kaybı olan bireyler tarafından rahatsız edici fenomen olarak algılanan ve yaşanan duyumların hala kendi karanlık tarafları ve tedavi eksikliği vardır. PG'nin bu deneyime ışık tuttuğu çıkarımı yapılamasa da, IPA'nın bulguları hayalet duyumların uzuv kaybıyla anlamlandırmaya uygun olarak yorumlanabileceğini göstermiştir. Örneğin, PG'siz Erdem ve Sabri fantom ağrılarını diğer katılımcılara göre daha az rahatsız edici olarak yorumladılar. Bu nedenle, yas danışmanlığı ve kayıplarına anlam verme, hayalet ağrının azalması adına faydalı olabilir.

Ayrıca IPA, uzun süreli yas literatürü için öncü bir çerçeve sağlamıştır. Bunlara ek olarak elde edilen bulgular, amputasyonun ölüm ve yaşam arasında bir köprü olabildiğini, uzuv kaybıyla yas tutmanın amputasyon öncesi yaşamla maliyeti ve uzuv kaybıyla gelen değişikliklere uyum sağlama gerekliliği olduğunu göstermiştir. Dahası, amputasyonda dini başa çıkma ve anlam vermenin rolüne dair sağlam kanıtları destekledi. Ek olarak, fiziksel iyilik halindeki değişikliklerle duygudurum dalgalanmaları, kendine, başkalarına, topluma ve dünyaya bakışın değişmesi, bağımsızlığın ve hareketliliğin yeniden kazanılması, hayalet uzuv ağrısı deneyimi de sesleriyle bildirildi. Öte yandan, bulgular Türkiye'de yaşanan engellilik deneyimine ikna edici kanıtlar sunmaktadır. Engelli bireyler ayrımcılığa ve damgalanmaya maruz kalırken aynı zamanda hayata tutunma sebebi olabilecek sevdiklerinin desteğini de aldılar.

4.5. Sınırlılıklar ve Gelecek Çalışmalara Öneriler

Mevcut tezin çeşitli sınırlamaları vardır. Her şeyden önce amputasyon, sadece hakkında konuşmayı deneyimleyenler için değil, aynı zamanda bir aile üyesi ve hatta bir görüşmeci olarak şahitlik yapmaya da meydan okuyanlar için hassas bir konudur. Bu noktada seçilen araştırma yöntemlerinin bu çalışma için uygunluğu tartışılabilir. Amputasyondan veri toplamanın zorlu bir süreç olması ve örneklem sayısının oldukça altında olması nedeniyle geçersiz ve eksik veriler nedeniyle planlandı. Bu nedenle sonuçlar ön sonuçlar olarak yorumlanabilir. Öte yandan, protez merkezinden ve çevrimiçi duyurular yoluyla toplanan veriler, yalnızca protez kullanmayı planlayan amputelere ulaşmak ve ayrıca interneti etkin kullanmak, psikolojik çöküntü yaşayan diğerlerine göre daha işlevsel olmak açısından önyargılı olabilir. Öyleyse; örneklemin temsilcileri bu çalışmanın bir başka tartışmalı konusu olabilir. Bulgular, klinik olarak

uzun süreli yastan muzdarip amputeler için genellenemez. Amputeler öz bildirim nedeniyle psikolojik yüklerini kendi başlarına hatırlayarak psikolojik durumlarını yeniden değerlendirmekte sorun yaşayabilecekleri soru sayısından şikayetçiydiler. Ayrıca, kesitsel çalışma tasarımının, neden-sonuç ilişkisini ve farklı aşamalarda uzun süreli yastın prognozunu engelleyen kendi sınırları vardır. Boylamsal çalışmalar, ampute örneğindeki katılımcılar arasında değil, katılımcıların yaşadıkları değişimlere ışık tutabilir.

Ayrıca, YFA katılımcıların deneyimlerini kelimelere döküp ifade edemedikleri ve görüşmecinin, katılımcıları deneyimlerinin önemli bölümleri hakkında konuşurmak için önemli sorular sorup sormadığı, amputasyonun yaşanmış deneyimi için tartışmalı bir metodoloji olabilir. Yas tutanların kederlerini çözümlemenin merkezinde anlamlandırma yattığı için (Worden, 2018), YFA, ampütelerin hayatındaki kaybın anlamını kavramak için sınırlı bir metodoloji olarak görülebilir. Ancak anlatılar veya yaşam öyküleri ile anlaşılabilir. Bununla birlikte, literatüre katkıda bulunmak için veri toplamak ve analiz etmek için seçilen her metodolojinin kendi sınırları vardır, bu iyi bilinen bir olumsuz etkidir. IPA dışında, söylem analizi veya anlatı analizi, amputasyon deneyimini daha iyi anlamak için, konuşmalardaki sessizliklere anlam vermek ve aynı zamanda tuhaf olaylara kendi benzersiz anlamlarını vermek için tam bir yaşam öyküsü toplamak açısından yararlı olabilir. Gelecekteki araştırmalar için farklı yöntemler kullanılabilir. Ayrıca, YFA temsili bir örneklem elde etmeyi değil, bireylerin belirli bir fenomeni nasıl deneyimlediklerini seslendirmeyi amaçlamıştır.

Başka bir bakış açısıyla, uzuv kaybı olan bireylerde PG için özel kriterler yeniden düşünülmelidir. Sevdiklerinin kaybı ve yas süreçlerinden farklı olarak, psikolojik yaraların onarılmasından önce bedenin fiziksel olarak iyileşmesini gerektiren beden benliğinde bir kaybı beraberinde getiren uzuv kaybıdır. Worden (2018, s.22), keder duygusunun damgalanmasına odaklanmamak için çeşitli aşamalardan ve farklı hızlardan geçen bir süreç olarak yastın önemine işaret ederek “anormal keder” yerine “ karmaşık yas” terimini seçmiştir. Bu nedenle yas tutmanın zaman sınırı tartışmalı bir konudur. Bununla birlikte, Dünya Sağlık Örgütü (ICD-11) için kayıptan 6 ay sonra, Amerikan Psikiyatri Birliği (DSM-5) için kayıptan 12 ay sonra ve 6 ay sonra zaten tartışmalı bir konu olan uzamış ampute yas için olası tanı süresi yeniden düşünülmelidir. keder araştırmacıları için kayıp. PG olarak teşhis edilmeden önce,

amputelerde "normal" yas tutma süresinin araştırıldığı ileri çalışmalar gerekliydi. Amputelerin mesleklerine geri dönmeleri, işlevselliğini yeniden kazanmaları üzerine odaklanan çalışmalarda kesme noktası olarak ampütasyondan 2 yıl sonra alınmıştır (Schoppen ve ark. 2001). İşlevsellik, PG tanısını belirleyen önemli bir kriterdir. Bu nedenle amputasyon sonrası işe geri dönme süresi 2 yıl, yasin tamamlanması ve ampütelerin uyumu hakkında ipucu verebilir.

Ek olarak, bu çalışma dini başa çıkmanın önemini göstermiştir ve daha sonraki çalışmalar dini başa çıkma türlerine ve bunun ampütelerin ruh sağlığı üzerindeki etkisine odaklanabilir. Amputasyon sonrası dini inanç, dindarlık düzeyi ve inanılan dindeki değişimler rehabilitasyon sürecinin prognozu için kavranması gereken önemli bir soru gibi görünmektedir.

Ayrıca, PG olasılığı açısından ihmal edilen amputeler, sağlık durumlarına ulaşamama riski altında olabilir. Pomeroy, Coudane, Dap ve Dautel (2020), komplike yası olan amputelerin nöroma rezeksiyonu veya güdük revizyon cerrahisi geçirme olasılığının daha yüksek olduğunu göstermiştir. Beden-zihin ikiliğinde, bireylerin bedenlerinden etkilenen sadece psikolojik durumları değil, psikolojik sıkıntıların da bedeni olumsuz etkilerinden etkilenebilmektedir. Uzun süreli yas tedavi edilemez ve tespit edilmesi vücudun geri kalanında hasara neden olabilir. Bu nedenle yeni cerrahi kararlara varılmadan ampütasyonda PG olasılığı ortadan kaldırılmalı ve gerekirse uygun tedavi sağlanmalıdır.

4.6. Sonuç

Bu tezin çıktılarının ampütelerin daha iyi rehabilitasyonu ve psikolojik sağaltımı için önemli olabileceği düşünülmektedir. Özellikle kayıp ve yas çerçevesi üzerinden, hem UYB'yi bir tanı olarak ampütelerin deneyimlediği psikolojik zorluklara ve fantom ağrılara bir çözüm önerisi hem de bu tanı ve deneyime yaslanarak da yas terapisini seçenek olarak sunmaktadır. Çünkü her kayıp beraberinde kaçınılmaz olarak yas sürecini de getirmektedir.

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I: APPROVAL OF THE METU HUMAN SUBJECTS ETHICS COMMITTEE

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